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**Women with bipolar disorder and pregnancy  
factors influencing their decision-making regarding treatment**

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*Awarding institution:*  
King's College London

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**Women with bipolar disorder and pregnancy:  
factors influencing their decision-making  
regarding treatment**

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# Abstract

**Background:** Women with bipolar disorder (BD) face an increased risk of suffering a severe episode of illness in the perinatal period, requiring them to make difficult choices regarding pregnancy. Decisions are made more difficult by a lack of research, particularly on the teratogenicity of psychotropic drugs. The studies in this thesis aimed to explore women's views on making these decisions, together with the views of health professionals who treat them.

**Methods:** 1) a systematic review and meta-synthesis of the qualitative literature on motherhood for women with severe mental illness (SMI); 2) a qualitative study of women with BD's views on pregnancy via individual interviews and an online forum; and 3) qualitative studies of health professionals' views via a focus group and Individual interviews.

**Results:** The review identified 23 studies on the views of women with SMI, and eight papers on professionals' views. Themes identified included *guilt, stigma* and *problems with service provision*. In the second study (21 women interviewed, 50 internet contributors), *centrality of motherhood, contextual factors, stigma* and *fear* were major themes. *Fear* and *stigma* were among themes echoed in the studies with perinatal specialists (11) and general psychiatrists (14). The idea of a decision aid was broadly welcomed by all three groups.

**Conclusions:** This thesis highlights the complexity of the challenges facing women with BD when they have children and the ways in which issues such as stigma and fear mitigate against the establishment of a meaningful therapeutic relationship with health professionals. Improved access to information and specialist advice is needed and research on the possible usefulness of a decision aid would be helpful. It is further suggested that many health professionals would benefit from more training on this topic to better understand the particular importance of BD in the perinatal period and to reduce stigmatizing attitudes.

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## Published papers

Dolman, C., Jones, I. and Howard, L.M., 2013. *Pre-conception to parenting: a systematic review and meta-synthesis of the qualitative literature on motherhood for women with severe mental illness*. Archives of women's mental health, 16(3), pp.173-196.

Dolman, C., Jones, I.R. and Howard, L.M., 2016. *Women with bipolar disorder and pregnancy: factors influencing their decision-making*. British Journal of Psychiatry Open, 2(5), pp.294-300.

[Copies attached in back of bound version]

## Abbreviations

**BAS:** Behavioural Activation Scale

**BD:** bipolar disorder

**CEDAR:** Clinical decision-making and outcome in routine care for people with severe mental illness

**CPD:** continuous professional development

**CPN:** community psychiatric nurse

**DSM:** Diagnostic and Statistical Manual of Mental Disorders

**IOPPN:** Institute of Psychiatry, Psychology and Neuroscience, King's College London

**MBU:** Mother and Baby Unit

**MDD:** major depressive disorder

**MMHA:** Maternal Mental Health Alliance

**NICE:** National Institute for Health and Care Excellence

**ONS:** Office of National Statistics

**OR:** odds ratio

**PDA:** patient decision aid

**PND:** postnatal depression

**PICU:** Psychiatric Intensive Care Unit

**PP:** postpartum psychosis

**SD:** standard deviation

**SDM:** shared decision-making

**SMI:** severe mental illness

**SSRIs:** selective serotonin reuptake inhibitors

**95%CI:** 95% confidence intervals



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# 1 Introduction and Background

The long-term condition bipolar disorder (BD) affects an estimated 1-2% of the population (2007). It is characterized by recurring episodes of manic, hypomanic and depressive symptoms (American Psychiatric, 2013), with relatively symptom-free intervening periods (Jann, 2014). BD is a severe condition, illustrated by the fact that the suicide risk for people with BD is about 20-30 times greater than that for the general population (Pompili et al., 2013). In addition to the considerable burden of disease it inflicts on sufferers, it is estimated to cost the UK economy at least £2 billion annually (at 1991/2000 prices, (Gupta and Guest, 2002). Its cause is not entirely clear (Goodwin and Jamison, 2007), though there is some evidence for the importance of genetic factors from large-scale genome association studies (Craddock and Sklar, 2013) and twin studies (Bootsman et al., 2016). Risk factors for relapse include stressful life events and poor medication adherence (Amann et al., 2015), and sleep dysregulation (Ritter et al., 2015). Most studies report an almost equal gender ratio in prevalence (Di Florio and Jones, 2010), which means that of the current population approximately 650,000 women in the UK will experience an episode of BD in their lifetime.

The major distinction between men and women with this condition is the impact that reproductive life events, particularly childbirth, have on women with this diagnosis. The postpartum period is associated with the highest lifetime risk of hospitalization for women with BD (Munk-Olsen et al., 2009). Around 35% suffer a recurrence of illness postnatally (Wesseloo et al., 2015), including approximately 20% who suffer the severest form of perinatal psychiatric illness, a postpartum psychosis, which can threaten the life of a mother and sometimes her child (Jones et al., 2014, Oates, 2003).

This subject is of particular interest to me because of my personal experience as a woman with BD who has had two pregnancies (one followed by hospitalization for postpartum psychosis). I have also co-led workshops for women with BD and their partners through my association with the charity Bipolar UK and currently campaign for better perinatal mental health services as Vice Chair of the Maternal Mental Health Alliance (in the interests of full disclosure, I am also a trustee of APP – Action on

Postpartum Psychosis). These roles have made me acutely aware of service shortcomings in this area and the gaps in the research base and have compelled me to contribute to addressing them.

Understanding how decisions in this complex area of healthcare are reached and identifying the obstacles which women and health professionals encounter could inform the development of better information and advice for these women and their partners and lead to improvements in services. I believed I was well-equipped as a service user researcher to investigate this topic because of my detailed personal knowledge of the subject and the advantages my personal experience brought to the study in terms of aiding recruitment and eliciting rich data from interviews with women with BD. The benefits of service user involvement in research have been demonstrated by an international systematic review (Brett et al., 2014). They included 66 studies and reported beneficial impacts at all key stages of the research process, together with some challenging ones. Also, a study that looked specifically at the impact of patient involvement in mental health research in the UK by examining all studies listed on the Mental Health Research Network's database (374) found that those that involved patients to a greater extent were more likely to have achieved their recruitment targets (Ennis and Wykes, 2013). The evidence base for impact remains weak but has grown in recent years as more studies address this subject (Hitchen and Williamson, 2015, Parkes et al., 2014, McKenna, 2015).

This chapter presents a review of the literature on bipolar disorder in relation to pregnancy and childbirth. It aims to provide background on the prevalence of BD and the elevated risk of relapse for this population during the perinatal period and introduce some of the issues women may be concerned about including medication in pregnancy and postpartum, obstetric and neonatal outcomes, longer-term effects on the child, and stigma, particularly in relation to health professionals.

## **1.1 Bipolar Disorder**

### **1.1.1 Prevalence and impact of bipolar disorder**

BD often entails a significant burden for those affected as well as high societal costs related to healthcare, absence from employment and early retirement (Ekman et al., 2013). It is associated with functional and cognitive impairment (Samamé et al., 2014), negative health outcomes (Fagiolini et al., 2013) and premature mortality (Tondo et al., 2003). The mean age of onset is in late adolescence and early adulthood (Merikangas et al., 2011). Suicide rates in individuals with BD are 20-30 times higher than in the general population (Pompili et al., 2013). A spectrum of bipolar disorder has been identified ranging from the relatively mild mood swings of cyclothymia to the more severe and debilitating bipolar 1 and bipolar 2 disorders (American Psychiatric, 2013). BD-type 1 is characterized by at least one manic episode in addition to depressive and hypomanic episodes (American Psychiatric, 2013). This distinguishes it from BD-type 2 which involves recurrent depressive episodes together with at least one hypomanic episode. A systematic review and meta-analysis found pooled lifetime prevalence of BD type 1 to be 1.06% (95% confidence interval [95%CI] 0.81-1.31) and that of BD type 2 to be 1.57% (95%CI 1.15-1.99) (Clemente et al. 2015). Approximately two thirds of people with BD have at least one comorbidity, most commonly anxiety disorders, substance misuse disorders, or impulse control disorders (Merikangas et al., 2011). The mainstay of treatment for bipolar disorder is pharmacological, including mood stabilizers such as lithium and sodium valproate, antipsychotics like olanzapine or quetiapine, and anti-epileptic medications like lamotrigine. These are sometimes supplemented with antidepressants. The National Institute for Health and Care Excellence (NICE) guideline on bipolar disorder recommends medication is used in conjunction with psychological therapies and psychoeducation (Kendall et al., 2014).

### **1.1.2 Gender differences**

Unlike unipolar depression, which is twice as common in women as men, prevalence in Bipolar 1 is similar in men and women according to the most recent epidemiological study in the US, using a representative adult sample ( $n = 36,309$ ) (Blanco et al.).

Prevalences of 12-month and lifetime DSM-5 bipolar 1 disorder were 1.6% and 2.2% for men and 1.5% and 2.0% for women. However there are differences in patterns of comorbidity (BD in males is more associated with substance abuse, in women with anxiety; more women than men suffer from rapid cycling and mixed episodes (Di Florio and Jones, 2010). BD is associated with the highest risk of suicidal behaviour, yet an international BD task force which conducted a meta-analysis found that women with BD are more likely to attempt suicide (OR = 1.54) while men are more likely to complete (OR = 1.83) (Schaffer et al., 2015). The higher number of attempts among women may be partly due to more females having a depression-prone course of illness, but could also be affected by sampling bias as men with BD were under-represented in the 34 studies included, accounting for only 36.7% of all subjects in the studies reporting suicide attempts. The major difference for women with BD in terms of course of illness is the impact of reproductive life events as there is consistent and well-replicated evidence of a relationship between episodes of bipolar disorder and childbirth (Di Florio et al., 2013, Jones and Craddock, 2005, Jones and Cantwell, 2010).

## **1.2 Bipolar Disorder, Pregnancy and Childbirth**

### **1.2.1 Risk of relapse in the perinatal period**

Most women with BD become mothers (Howard et al., 2001, 2005) and are at high risk of having an episode of illness in relation to pregnancy and childbirth. In a UK study including 1,212 parous women with BD, more than two thirds (69%) reported at least one episode of illness during pregnancy or within 6 months of childbirth (Di Florio et al., 2013).

### **1.2.2 Risk of relapse during pregnancy**

The effect of pregnancy on BD has been examined by a number of studies, both prospective and retrospective, but with inconsistent results (Viguera et al., 2000, 2007, 2011b, Newport et al., 2012b, Freeman et al., 2002). Whether a woman with BD is vulnerable to relapsing in pregnancy is complicated by her medication use: whether she is medication free, switches or changes her dose, or stops (which can trigger an episode, especially if she stops abruptly) (Viguera et al., 2007, Newport et al., 2012a). In a seminal study, Viguera and colleagues (2000) examined whether it was medication cessation due to fears about teratogenicity which triggered perinatal episodes of BD by retrospectively comparing the risk of relapse in pregnant and non-pregnant women with BD following discontinuation of lithium maintenance treatment. The illness recurrence rates were similar during pregnancy and the equivalent period for non-pregnant women, but postpartum recurrences were nearly 3 times more frequent than recurrences in the non-pregnant cohort during the equivalent period post cessation (70% vs 24%). The researchers concluded that pregnancy had a neutral effect on the course of BD but there appeared to be a 'postpartum trigger' that was not merely the result of stopping medication.

More recent population-based studies suggest that pregnancy may be protective with low rates of both new onset of illness (Sharma and Pope, 2012) and relapse during pregnancy (Munk-Olsen T, 2009) reported. Other studies have produced conflicting results, for example Viguera's group reported high recurrence rates in pregnancy, particularly for those women who discontinued prophylactic medication (85% of 62 women) (Viguera et al., 2007). However when they investigated a larger more representative sample (621), 23% were recorded as becoming ill during pregnancy compared to 52% with a postpartum episode (Viguera et al., 2011a). As mentioned before, it is difficult to provide an accurate assessment of the risk of relapse in pregnancy without accounting for medication use, especially as women may stop their medication abruptly due to fears of harm to the foetus and this might itself cause a 'rebound' effect (Jones et al., 2014). A study in 2013 of 980 women with BD-type 1 found that only 8% of perinatal episodes had their onset in pregnancy though the

retrospective design of the study meant that researchers were not able to gather reliable information on the pharmacotherapy used (Di Florio et al., 2013).

### **1.2.3 Risk of postpartum relapse**

Di Florio and colleagues' finding corroborated the results of a large study employing the Danish admission and birth registries that examined over 600,000 pregnancies and postpartum periods. Women were over 23 times more likely to be admitted with an episode of BD in the first postpartum month than at other times in their life (RR=23.33, 95% C.I.s 11.52– 47.24 (Munk-Olsen et al., 2006). A previous history of admission with bipolar disorder was associated with an even larger increased risk of admission following pregnancy, with 26.9% of all Danish women with BD with previous psychiatric admission(s) readmitted during their first year postpartum, a figure almost twice as high as that for women with schizophrenia-like disorders (15.7%) (Munk-Olsen T, 2009). Again, these studies were not able to identify the effect of medication use indicated by Viguera's (2000) study, but an Italian group tried to overcome the problems of confounding by medication use by recruiting a clinical sample of women with BD who were medication-free during their pregnancies and early postpartum (Maina et al., 2014). Reporting data on 276 women gathered over 15 years, 75% of them suffered a mood episode within four weeks of delivery. Depression was the most frequent morbidity following pregnancy (n=165, 79.7%); manic episodes occurred in 28 patients (13.5%), mixed episodes in 8 subjects (3.8%), and hypomanic episodes in 6 women (2.9%). The prevalence of suicide attempts in postpartum episodes was 11.6%. The high rate of postpartum morbidity in un-medicated women corroborates the findings of Freeman and colleagues (2002) who found a morbidity rate of 67%. This evidence indicates that medication effects are likely to explain observed differences in postpartum relapse rates between treated and non-treated pregnant women and, as most studies include both groups, the rates recorded are lower. For example, a systematic review and meta-analysis of 37 studies concluded that a third of women with BD were at high risk of a postpartum relapse (37%) (Wesseloo et al., 2015).

### **1.2.4 Risk of postpartum psychosis**

Women with BD are at risk of postpartum psychosis (PP) a potentially dangerous illness, defined as occurring in the first 3 months after childbirth (Jones et al., 2008, 2014). Also called puerperal psychosis, it is not categorized as a separate condition by DSM-5 (American Psychiatric, 2013), though strong arguments have been made that it should be (Jones and Cantwell, 2010). A number of studies have estimated the risk of PP to be about 1-2 per 1000 births based on postpartum admissions to psychiatric hospital (Munk-Olsen et al., 2006, Kendall et al., 1987, Terp and Mortensen, 1998). However, this is only an approximation of prevalence as not all postpartum psychiatric admissions are due to PP, and a proportion of episodes are treated at home (especially if there is no local provision for admission with the baby).

The strong link between bipolar disorder and vulnerability to PP is clear. Data from both retrospective and population registry studies corroborate this (Wesseloo et al., 2015, Munk-Olsen et al., 2009, Jones and Craddock, 2005). In a study that included 1212 parous women with BD, Di Florio and colleagues reported the risk increasing from one in a thousand deliveries for the general population to approximately one in five deliveries for those with BD-type 1 (Di Florio et al., 2013). For those with a family history of postpartum psychosis, the risk of suffering a PP has been put as high as 57% (Jones and Craddock, 2001b, Robertson et al., 2005). However, 50% or more of women who suffer a PP have no psychiatric history suggesting they would be at high risk (Blackmore et al., 2013). Postpartum psychosis most commonly takes the form of mania, severe psychotic depression, or mixed episodes with psychotic features and is characterized by rapid onset and escalation after childbirth (Heron et al., 2008, Jones and Smith, 2009). This condition usually requires hospitalization and in rare cases can lead to maternal suicide (Knight et al., 2014) and infanticide (Spinelli, 2004, Oates, 2003).

The level of risk of a perinatal episode of illness is also associated with primiparity (Jones and Craddock, 2005, Di Florio et al., 2013), and a diagnosis of BD-1 more than BD-2. Di Florio and colleagues reported that 49.8% of their cohort of 980 women with BD-1 had a perinatal mood episode (pregnancy 8.6%, postpartum period within 12



months of childbirth 91.3%), compared to 42.2% of the 232 women with BD-2 (pregnancy incidence 18.4%, postpartum up to 12 months of childbirth 81.6%) (Di Florio et al., 2013). The reason for this strong association between childbirth and relapse in women with BD is not known, though it has been hypothesized with some support that it is a combination of genetic, hormonal and possibly sleep-related factors (Jones et al., 2014, Bloch et al., 2000, Sharma and Mazmanian, 2003). Family studies of postpartum psychosis consistently demonstrate familial aggregation of affective disorder (Jones and Craddock, 2001b, Blehar et al., 1998) and Jones and colleagues have identified regions of interest on specific chromosomes associated with susceptibility to bipolar affective PP which supports the hypothesis that vulnerability to episodes of PP is influenced by genetic factors (Jones et al., 2007).

The high incidence of episodes immediately after childbirth already discussed, together with their rapidity of onset (Maina et al., 2014) has led to speculation that the drop in oestrogen and progesterone levels that occurs after delivery is implicated in some way. Bloch and colleagues (2000) provided evidence of the involvement of these hormones in postpartum depression by simulating the hormonal effects of childbirth in eight non-pregnant women by administering doses of oestradiol (synthetic oestrogen) and progesterone for 8 weeks and then withdrawing both steroids under double-blind conditions. Five of the eight women with a history of postpartum depression developed mood symptoms, whereas none of those without such a history did so. It has also been hypothesized that sleep might play a role in the development or worsening of episodes of postnatal illness in women with BD. Sharma and Mazmanian (2003) reviewed the literature on the relationship between sleep disruption and postpartum psychosis and suggested that sleep loss may be the final common pathway in the development of psychosis in susceptible women.

Wesseloo and colleagues' systematic review and meta-analysis included 37 studies describing 5,700 deliveries in over 4,000 patients who had a history of BD, PP or both (Wesseloo et al., 2015). The overall postpartum relapse risk for women with BD was 37% (95% CI = 29, 45), and 31% (95% CI=22,42) for women with a history of PP. There was insufficient information to determine relapse rates for patients with BD *and* a

history of PP, with information provided by only three small studies: the relapse rate was 87% in one (45/52 patients) (Maina et al., 2014), and 50% in each of the other two studies (2/4 patients (Pfuhmann et al., 1999) and 4/8 patients (Bergink et al., 2012). It is important to note that in the review only 17% of reported relapses were defined as 'severe', with the remaining 83% suffering nonpsychotic affective episodes (mostly depressive and some hypomanic episodes). This large meta-analysis suffered from the considerable heterogeneity of studies included, most of which had made no adjustments for confounding such as medication use. It also included retrospective studies which have potential for information bias, and prospective studies which are biased towards underestimation of relapse risk due to selection bias. However, it also included birth register studies which are more likely to provide better estimates of relapse rates (though they usually rely on inpatient admission as a marker of relapse so tend to record lower rates than cohort studies).

### **1.2.5 Risks of medication in pregnancy**

As indicated above, an important factor to potentially reduce relapse is likely to be whether a woman takes medication during pregnancy and/or in the immediate postpartum period. A woman with BD may decide to stop her prophylactic medication because she wants to minimize the potential risk to her fetus, as all psychotropic medication crosses the placenta. A recent Danish register-based retrospective cohort study of 336 pregnant women with BD found that the proportion of women redeeming prescriptions for any psychotropic drug decreased significantly during pregnancy, from 54.8% in the 3 months preconception to 35% in the third trimester (Broeks et al., 2017). But stopping medication, especially abruptly, itself carries a risk as it greatly increases a woman's chances of relapsing which might necessitate more aggressive treatment or even abortion. In a prospective study of 89 pregnant women with BD, the risk of at least one recurrence in pregnancy was twofold greater among women who discontinued versus continued mood stabilizer treatment, and the proportion of weeks ill during pregnancy was five times greater (Viguera et al., 2007). Wesseloo and colleagues had similar results in their systematic review for the postpartum. They were

able to stratify postpartum relapse rates by pharmacotherapy during pregnancy in 445 women. Women without prophylactic pharmacotherapy during pregnancy had a relapse rate of 66% (95% CI=57, 75) compared to 23% (95% CI=14, 37) for women with prophylaxis, adding weight to the argument that medication during pregnancy in women with BD appears to be important for postpartum relapse prevention as well as the maintenance of mood stability during pregnancy (Wesseloo et al., 2015).

#### **1.2.5.1 Shortcomings of the evidence base**

Clinicians advising a woman facing the potentially life-changing decision whether or not to stop taking her medication are hampered by the paucity of the research base, particularly on the potential teratogenic effects of the various medications used to treat BD. The lack of reliable evidence on the safety of psychotropic drugs in pregnancy is due in part to the problems of conducting clinical trials in this population (Unger et al., 2011). Most randomized controlled trials on the efficacy of medications have excluded women who are pregnant or breastfeeding (Howard et al., 2017). Generally, guidelines (for example NICE, 2014 and the British Association for Psychopharmacology's guidance, 2017) have extrapolated findings from non-pregnant samples. Studies on women in the perinatal period have often been conducted on small samples with significant methodological limitations due to major confounding and bias (Khalifeh et al., 2015a). Further, most studies on adverse impacts of psychotropic medication on the foetus are either not stratified according to diagnosis or focus on women with depression (Cohen et al., 2006), and for some drugs like the anticonvulsants, the populations studied have been predominantly women with epilepsy rather than BD. Interpreting the few studies that describe the effects of medication on pregnant women with BD is further complicated by variable inclusion criteria: 'bipolar disorder' including BD-1 and BD-2; Bipolar-1 only; or 'bipolar disorder' including the wider BD spectrum. The unreliability of the evidence on what drugs can be taken safely during pregnancy and breastfeeding and how to weigh that risk against the possible consequences of having a relapse of illness is likely to be a significant concern of women with BD contemplating pregnancy so it is useful to review the evidence on medications commonly taken by this population. When considering risk

estimates (and describing them to pregnant women), it is also important to be aware that the background malformation rate in the general population is between 2 and 4% (Dolk et al., 2010).

#### **1.2.5.2 Lithium**

Lithium is the most effective known mood stabilizer and has long been considered the 'gold standard' treatment for BD (Geddes and Miklowitz, 2013). However, in the past, there has been considerable confusion and concern about the risk of congenital malformations in the fetuses of women who have taken lithium during pregnancy, particularly the risk of Ebstein's anomaly (a heart valve defect). This was largely based on a study conducted by Schou and colleagues (1973), which collected data from a registry of voluntarily submitted cases, and was therefore subject to significant selection bias. By the 1990s, this study had been discredited (Cohen et al., 1994, Bergink and Kushner, 2014) and the risk to an exposed fetus of cardiac malformations is now thought to be lower: carrying an estimated 7 per 1,000 increased risk of any congenital abnormalities (Munk-Olsen et al., 2018, Paterno et al., 2017). The impact of confounding was reported by a recent large surveillance study of 5.6 million births in Ireland which identified 173 cases of Ebstein's anomaly, unexplained by other causes, and found an association with maternal mental health problems but not with lithium exposure (Boyle et al., 2017).

Similarly, a systematic review of lithium toxicity which identified 7 case control and 7 cohort studies with data on teratogenicity concluded that the evidence that exposure to lithium is teratogenic is weak and the risk has been overestimated (McKnight et al., 2012). The authors suggested clinical guidelines which recommend avoiding lithium in pregnancy should be reviewed in favour of a consideration of the relative risks of continuing or stopping. A number of studies in high-risk women provide some support for the benefits of lithium prophylaxis during pregnancy and the postpartum period (Viguera et al., 2000, 2007, Bergink et al., 2012, Wesseloo et al., 2015). In all cases, most authorities currently advocate that the benefits of medication for relapse prevention need to be carefully weighed against the risk for the foetus during

pregnancy, neonatal complications and breastfeeding in the postpartum period, taking into account the woman's psychiatric and family history (Burt et al., 2010, NICE., 2014).

#### **1.2.5.3 Valproate**

The situation regarding another frequently prescribed medication for BD, sodium valproate, is now clearer with firm instructions issued by the UK's MHRA (Medicines and Healthcare Products Regulatory Agency) to avoid prescribing it to women of childbearing age due to its proven teratogenic effects (of babies whose mothers take sodium valproate during pregnancy, up to 10% are at risk of having a birth defect, and up to 40% have learning and developmental problems (Agency, 2017). This message reinforces the recommendations of NICE (Howard et al., 2014), but as this information is disseminated throughout the medical profession, it is possible that women with BD of childbearing age are still being prescribed valproate, whilst others choose to continue taking it in the absence of any other medication proving beneficial (Calabrese and Delucchi, 1990).

#### **1.2.5.4 Lamotrigine and carbamazepine**

Like Valproate, lamotrigine and carbamazepine are antiepileptic drugs also used as mood stabilizers in BD. However, comparative studies on their relative teratogenicity have shown them to be less dangerous than valproate. For example, a 15 year prospective observational study in Ireland from 1996 to 2012 involving over 5,000 women with epilepsy reported that valproate carried a significantly higher risk of major congenital malformations (MCMs) than either lamotrigine ( $p=0.0001$ ) or carbamazepine ( $p=0.0001$ ) monotherapy (Campbell et al., 2014). The indication that these two medications are safer treatment options in pregnancy than valproate has been corroborated by a recent study involving 240,071 women in the UK. Petersen and colleagues (2017) found the prevalence of MCMs was similar for women prescribed lamotrigine and carbamazepine compared to women with no antiepileptic

drug in pregnancy (2.7%, 3.3% and 2.2% respectively), whereas for women prescribed valproate the prevalence was fourfold higher.

#### **1.2.5.5 Antipsychotics**

Less is known about the effects of antipsychotics on the foetus, though a prospective cohort study by Habermann et al. (2013) did not reveal a major teratogenic risk for second-generation antipsychotic agents, concluding that the better studied drugs of this group were a treatment option during pregnancy. A 2015 review and meta-analysis suggested that women requiring antipsychotic treatment during pregnancy have a higher risk of adverse birth outcomes such as congenital malformations, unusually low or high birth weight, or preterm delivery (Coughlin et al., 2015). However, as most of the 13 included cohort studies had made limited or no adjustment for potential confounding, the authors concluded that there was insufficient data to attribute this association to medication exposure. Women taking antipsychotic medication in pregnancy are a high risk population for numerous reasons: they are more likely to be engaging in other potentially harmful behaviours such as smoking and/or substance use, and are also more likely to be suffering psychosocial stressors and medical comorbidities such as diabetes in addition to the effects of their underlying mental illness. Smoking can increase the risk of a host of adverse outcomes, including: congenital heart defects in offspring (Lee and Lupo, 2013); preterm delivery (Tong et al., 2017); overweight offspring (Oken et al., 2008); cardiovascular problems in offspring (Burke et al., 2017) ; miscarriage (Pineles et al., 2014), and impaired foetal brain development (Banderali et al., 2015). Cocaine use increases the risk of growth retardation and microcephaly (Smith and Santos, 2016) and alcohol abuse has many detrimental effects, notably fetal alcohol syndrome, a combination of growth restriction, characteristic facial features and cognitive impairment (Viteri et al., 2015). Diabetes (which is more common in this population because of higher rates of obesity often exacerbated by psychotropic drugs), is associated with an increased incidence of adolescent obesity (Pettitt et al., 1985) and related glucose intolerance in the offspring and impaired intellectual achievement (Rizzo et al., 1997).

Supporting this interpretation, a recent cohort study in the UK based on electronic health records reported that antipsychotic treatment in pregnancy carries limited risks of adverse pregnancy and birth outcomes once adjustments have been made for health and lifestyle factors (Stevenson et al., 2016). Their results supported previous associations between valproate and adverse child outcomes but they found no evidence of such an association for antipsychotics. This result was corroborated by a Canadian study which compared two large cohorts of women, one unmatched and one matched using a statistical technique called 'high dimensional propensity score matching', which aims to minimize unmeasured confounding (Vigod et al., 2015). In the unmatched cohort (1200 who used antipsychotics in pregnancy compared to 40 000 who did not), women who used antipsychotic medication had an increased risk of several adverse outcomes, including preterm birth (15%), gestational diabetes (8%), hypertension (5%) and large for gestational age infants (4%). However, in the matched cohort of 1021 women who were prescribed antipsychotics during pregnancy and 1021 who were not, none of these outcomes was associated with antipsychotic use, suggesting that the associations observed in the unmatched cohort were not due to antipsychotic use but rather to confounding (Khalifeh et al., 2015a). These results further suggest that severity of illness might be more important, together with other risk factors which are not usually reported but often associated with mental illness such as obesity, smoking, poor nutrition and domestic violence.

#### **1.2.5.6 Antidepressants**

Antidepressants are taken by a much larger number of women of childbearing age as depression affects twice as many women as men (Kessler and Bromet, 2013). Around 10% of women experience a major depressive illness or anxiety disorder but they often discontinue pharmacological treatment in the perinatal period because of fears over the safety of the fetus (Petersen et al., 2011). As a result, there have been many studies on the effects of antidepressants but, as is the case with antipsychotics, an often contradictory and confusing picture of teratogenicity has emerged, often adding to the anxiety of women faced with the decision of whether or not to take them in pregnancy. For example, one (much-publicised) study found children prenatally

exposed to SSRI antidepressants had more autistic traits and were at higher risk of developmental problems than children who were only exposed to depressive symptoms in pregnancy (El Marroun et al., 2014). As with the research on other medications discussed, this case control study with a group of only 69 children exposed to SSRIs, was severely criticized for methodological shortcomings and accused of being a 'red herring' which was likely to fuel further anxiety and guilt among women (Petersen et al., 2014a).

Methodological problems abound in this area and – as with the Canadian antipsychotic study described above - novel approaches are required. Such a stratagem was adopted by Furu and colleagues (2015) to examine the association between birth defects and antidepressant use (selective serotonin reuptake inhibitors -SSRIs - or venlafaxine) in the first trimester. They conducted a population-based cohort study using the registers of all 5 Nordic countries to extract data on 2.3 million live singletons (1.6% exposed infants), but also tracked a sibling cohort including 2288 singleton live births, who were discordant for maternal antidepressant use and for congenital malformations. After taking into account key confounders like maternal age, diabetes, use of other drugs, and self-reported smoking, exposed infants in the general cohort had a small increased risk of major birth and cardiac defects but in the sibling controlled analysis none of these outcomes was associated with exposure to SSRIs or venlafaxine (Odds ratios 1.15 (95% C.I. 1.05 – 1.20, in the covariate adjusted analysis and 0.92 (0.72 – 1.17) in the sibling controlled analysis). The researchers concluded that their results argue strongly against antidepressants having a teratogenic effect and that the small associations found in the whole cohort could be due to confounding by familial or lifestyle factors.

### **1.2.6 Risks of medication in the postpartum**

Decisions also need to be made about treatment with psychotropics after the delivery. Many women choose not to take medication during their pregnancy to protect the foetus from the possibility of harm, but decide to resume treatment immediately after the birth to try to protect against becoming ill due to the postpartum 'trigger'



associated with BD. This can conflict with a desire to breastfeed as all medications cross the placental barrier to a greater or lesser extent though data to guide the use of psychotropic medication during lactation are sparse (Bogen et al., 2011, Fortinguerra et al., 2009). Moreover, the pressure to breastfeed from health professionals and society at large can complicate the decision for women with BD who are taking lithium, lamotrigine, or carbamazepine which can enter the breastmilk with potential harm to the baby (McAllister-Williams et al., 2017, Bauer and Gitlin, 2016). Those who are seeking preconception advice will therefore want to take their breastfeeding preferences into account when considering medication options. When deciding on medication at this time, they also need to take into account medication side-effects such as sedative properties which might adversely affect their ability to care for their infant.

### **1.2.7 Risk of adverse obstetric and neonatal outcomes for women with BD**

A recent systematic review of outcomes for BD in pregnancy and childbirth, which included 9 studies published between 2000 and 2015 (Rusner et al., 2016), concluded that adverse outcomes were common in women with BD and their infants, though a meta-analysis of results was not possible due to the heterogeneity of data, particularly the use of differing definitions of bipolar disorder. This review included a population-based cohort study in Ontario, Canada (including 1,859 women with BD) which addressed some of the confounding by lifestyle and other factors which make interpretation of the data in this area problematic. Mei-Dan and colleagues (2015) demonstrated that women previously hospitalized for BD are at increased risk of adverse perinatal outcomes compared with the general population. After controlling for maternal age, income, parity, infant sex, obesity, diabetes, hypertension, venous thromboembolic disease and obstetric complications, BD was associated with preterm birth (adjusted OR [AOR], 1.95; 95% confidence interval [CI], 1.68–2.26) and severe 'large for gestational age' (AOR, 1.31; 95% CI, 1.03–1.67). They also found a significant association with congenital malformations, neonatal morbidity, and neonatal hospital

readmission. Although study covariates explained some of the increased risk, a limitation of this study was its focus on the severe end of the BD spectrum only (for inclusion, women had to have been hospitalized within the 5 years preceding the index pregnancy), and the authors called for more research to investigate these associations further.

A similar large cohort study conducted in Australia found the risk of preterm birth and SGA (small for gestational age) was not higher among women with BD, but their diagnoses were based on inpatient and outpatient service use, suggesting a wider spectrum of illness severity in their cohort, which could explain the observed differences (Jablensky et al., 2005). Also, the Canadian group could not control for psychotropic drug use or other factors which might be associated with the lifestyle of a woman with a severe mental illness such as smoking, poor nutrition or motivation to obtain prenatal care. These studies illustrate the complexity of trying to unpick the statistical associations and generalized risk estimates which underpin advice given to women with BD making pregnancy decisions. In addition the Canadian study (in accordance with NICE guideline recommendations (2014)), indicates that lifestyle changes may also need to be discussed as part of preconception consultations to try to influence potentially modifiable risk factors such as obesity, diabetes, substance misuse and hypertension.

### **1.2.8 Possible long-term effects on the child**

In addition to the evidence of adverse perinatal outcomes for women with BD and the possible teratogenic effects of the various medications they might be taking, there are concerns about the longer term adverse effects on children born to women with BD. Some women are concerned about passing on the condition to their children, and the qualitative literature demonstrates that the condition's effect on the ability to parent successfully is a frequent concern for women considering starting a family (see chapters 2 and 3).

### **1.2.9 Genetic risk**

Bipolar disorder is a highly heritable disorder, with up to 85% of the variance in risk determined by genetic factors, and a positive family history remains the strongest predictive factor for development of the illness (Craddock and Sklar, 2013). Attitudes to genetic testing serve as an indicator of patients' feelings regarding passing on the condition and the results of two studies suggest that individuals with BD would look favourably on its introduction (though there was limited interest in prenatal testing), and a significant number were concerned about associated stigma (Jones et al., 2002, Meiser et al., 2008). Concerns over passing on their illness are discussed by mothers with BD in a number of qualitative studies (for example (Peay et al., 2009) which are described in chapter 2. Meta-analyses have shown that, compared with other children, the offspring of a parent with bipolar disorder have approximately a 1 in 10 chance of developing the disorder (Lapalme et al., 1997, Axelson et al., 2015).

### **1.2.10 Outcomes for children of a mother with BD**

As indicated above, not enough is known about the long-term effects of having been exposed to various medications in utero. A review of the maternal and foetal effects of antipsychotic drugs in pregnancy identified only four studies and concluded that the longer neurodevelopmental outcomes for children exposed in utero remain unclear (Galbally et al., 2014). But In the quantitative literature, there is evidence to demonstrate that parental mental illness itself - with or without the added complication of medication - can affect almost every aspect of child development, contributing to insecure attachment and impaired cognition from the time of exposure through to adult life (Murray, 1997, Manning and Gregoire, 2009). Postpartum depression has also been shown to have an effect on adolescent IQ (Hay et al., 2008) and predict offspring mental health problems in adolescence (Verbeek et al., 2012), and there is some evidence that exposure to antenatal depression elevates the risk (Pawlby et al., 2009). But there is also a multitude of moderating factors on the association between maternal mental illness and adverse child outcomes as a meta-

analytic review of 193 studies on maternal depression has demonstrated (Goodman et al., 2011). These include level of illness severity and chronicity, genetic factors, socioeconomic status, age of mother, child assessment source and child gender. However, some women are aware of these risks (Heron et al., 2012b) and this may influence their decision to become mothers. Much more research needs to be done to establish the significance and persistence of these effects as well as to tease out the relationship between the possible effect of the mother's illness and the myriad of factors – such as socioeconomic status, partner and familial support, illness severity and persistence – that might moderate it (Stein et al., 2014).

Murray and Cooper (1997) found that mothers who suffered postnatal depression reported greater rates of behavioural problems in their children at 18 months and 5 years of age compared with controls with no postnatal depression, though research of this type has not been conducted with a bipolar specific cohort. This is important in terms of chronicity, which may be moderated in women with BD who return to their usual treatment regime after the perinatal period. There is some evidence to suggest that mental illness in a parent can have a detrimental effect on the psychosocial and behavioural functioning of their offspring (Bella et al., 2011, Birmaher et al., 2009). A small Brazilian study (34 women with BD plus controls) conducted by Moreno et al (2012) with women who had at least one child aged 6-18 found that mothers with BD were less likely to have stable unions (45.5%;  $p < 0.01$ ) or to live with the biological father of their children (33.3%;  $p < 0.01$ ), and children of women with BD reported more physical abuse (16.1%;  $p = 0.02$ ) than offspring of mothers without psychiatric illness. Conversely, Reichart et al. (2007) concluded that parental rearing in families with a parent with BD (129 offspring of 80 BD parents) was no more dysfunctional, as perceived by their offspring, than in families from the general population.

A large well-designed meta-analysis of 33 studies including 3863 offspring of parents with severe mental illness (SMI) and 3158 controls has been conducted by Rasic and colleagues (2013). Results suggest that, by early adulthood, the offspring of someone with BD has a 1 in 3 risk of developing a psychotic or major mood disorder and a 1 in 2 risk of developing any mental disorder. The authors stress that, due to the limited

number of studies in this area, these results should be considered preliminary, but urge that people with SMI considering parenthood should be informed of the wider risk of offspring inheriting susceptibility to a broad spectrum of mental illness, not just the particular disorder with which their parent has been diagnosed.

### **1.3 Stigma**

Stigma is an all-pervasive presence in the lives of people with mental illness (Thornicroft, 2006) and as such is likely to have an influence on pregnancy decision-making. Individuals with SMI suffer discrimination in many realms: employment (Stuart, 2006), access to 'social capital' (Webber et al., 2014) and to public and private institutions (Corrigan et al., 2004). They suffer stigma from family members and social contacts (Rusch et al 2014) and their own anticipation of being stigmatized further exacerbates help-seeking and engaging with health and social services (Farrelly et al., 2014, Henderson et al., 2013, Clement et al., 2015). In the UK and other countries which have instigated comprehensive anti-stigma campaigns, such as Australia, the effect of stigma appears to be lessening (Thornicroft et al., 2016, Sampogna et al., 2017), but it is still a notable problem that hampers access to treatment in the NHS (Gronholm et al., 2017, Clement et al., 2015), including in relation to parenthood (Jeffery et al., 2013).

Some studies have highlighted stigmatization by health professionals as a problem (Lauber et al., 2006, Schulze, 2007). Jeffery and colleagues analyzed the results of a telephone-based survey of 304 community psychiatric service users (73% female) in 10 UK health trusts conducted in 2009 and 2010 who had all reported having experienced some level of discrimination in relation to parenthood in the previous 12 months (29% of the total 1047 service users who were parents or had enquired about starting a family) (Jeffery et al., 2013). Ten themes were identified, including ones related to being seen as an unfit parent; being stopped from having children and not being listened to. Themes related to both health and social care professionals and society at large, but the authors concluded that the evidence pointed to a need for anti-

discrimination training for professionals and greater support for parents with mental illness.

### **1.3.1 Stigma and bipolar disorder**

Specifically in relation to bipolar disorder, a systematic review (Ellison et al., 2013) identified 25 papers on stigma and concluded there was some evidence that BD was viewed more positively than schizophrenia and less positively than depression, though this result was challenged by a cross-sectional study conducted by Farrelly and colleagues (2014), who found that diagnosis had minimal impact on the level of discrimination experienced. Self-stigma, the process by which a person internalizes the negative attitudes of society with concomitant effects on her self-esteem and confidence to engage with others (Corrigan and Watson, 2002) is also relevant in this context. For example, a small cross-sectional study recently examined the relationship between self-stigma, treatment adherence and medication discontinuation (Hajda et al., 2016). Among 33 outpatients with BD they found that the level of adherence to pharmacotherapy positively correlated with age but negatively with self-stigma. Stigma can influence a woman's decisions about pregnancy in that her own perception that society would view her as an 'unfit' mother might discourage her from considering having children; or her anticipation of encountering stigmatizing attitudes from health professionals may deter her from seeking help.

## **1.4 Research on bipolar disorder and decision-making**

As decision making is central to this thesis, a chapter has been dedicated to exploring it in depth (Chapter 5) but, by way of background, it's important to outline what work has been done with a BD population. The amount of research into bipolar disorder generally is disproportionately low compared to other mental health disorders (Kirtley, 2014). Kirtley's analysis of the UK mental health research funding landscape from

2008 to 2013 revealed that BD research received only 1.5% of the total expenditure over those six years, compared to the 5.1% spent on schizophrenia research, despite its lower prevalence. 'Decision making' in the psychiatric literature is often concerned with exploring the neural and biological reasons why a mental illness like BD affects a person's cognition and impairs their decision-making abilities (Burdick et al., 2014, Adida et al., 2015). For example, Martino and colleagues found in a small study (85 euthymic patients with BD-1 or BD-2 and 34 healthy controls) that, despite memory and executive function deficits, those with BD had intact decision-making abilities, suggesting that poor decision making is not a trait marker of the disorder (2011).

Little attention has been focused on BD in the literature concerned with the pros and cons of 'shared decision-making', that is: how a person with a health condition makes decisions about their treatment in collaboration with a clinician (Edwards and Elwyn, 2009), though recently a systematic review of studies examining communication and decision making in mental health focused on bipolar disorder (Fisher et al., 2016). A total of 13 studies in outpatient settings that included a proportion of BD patients (ranging from 12 to 98% of the sample) were included with only two studies with BD-only samples, both addressing the association between therapeutic relationship and treatment adherence, (Sajatovic et al., 2005, Sylvia et al., 2013). Fisher and colleagues found that, despite strong patient preferences for involvement in consultations, it appears patients with BD are often less involved than they desire (Bilderbeck et al., 2014, De las Cuevas et al., 2014) and the reviewers called for more BD-specific research to be done in this area (see Chapter 5). A feasibility study has been successfully carried out on an electronic decision aid for long-term treatment decisions for people with BD which is now going to be trialled to see if it improves patient outcomes (Eiring et al., 2017).

#### **1.4.1 Bipolar disorder and decision-making in pregnancy**

Even less research has been conducted on BD and decision making in pregnancy. Indeed, having reviewed the evidence, authors of the NICE guidelines on antenatal and postnatal mental health stated: "more research is clearly needed to address the

particular issues around discussing psychotropic medication in pregnancy with women and their partners” (NICE., 2014). Regarding the efficacy of preconception advice for women with BD, only one study has been conducted, in the US in 2002 (Viguera et al.). Viguera and colleagues surveyed 70 women with BD after specialized consultation about treatment options and risks around pregnancy. Before consultation, 45% of the respondents had been advised not to become pregnant by a health professional; 21% by a spouse, and 45% reported that a relative had advised against pregnancy. However, after a consultation with a specialist perinatal psychiatrist, 63% of that group decided to pursue pregnancy, with two thirds becoming pregnant within 12 months. The most commonly reported reasons for deciding to avoid pregnancy (post consultation) were fear of the adverse effects of medication on the foetus and fear of illness recurrence. Another American group surveyed pregnant and postpartum women about their psychopharmacology decision making processes and communication experiences with obstetric/gynaecological healthcare providers (Price and Bentley, 2013). Researchers concluded that above all women wanted accurate, unbiased and complete information and a meaningful collaboration with their health provider, but as illness severity and diagnoses were unspecified, it is not possible to draw either SMI relevant or BD-specific conclusions.

Two small qualitative studies have been published on BD and parenting (Venkataraman and Ackerson, 2008, Wilson and Crowe, 2009). With community samples of 10 and 5 respectively, both studies reported women with BD’s concern about the impact their illness might have on their offspring, particularly in terms of inconsistency and disciplining their children. But they also identified strengths such as the advantages of hypomanic energy when parenting (Venkataraman and Ackerson, 2008). These were the only two studies published in this area with BD-only samples, so when I came to conduct a systematic review I decided to include the views of *all* women with severe mental illness. The resultant review and meta-synthesis is reported in Chapter 2.



## **1.5 The views of health professionals on treating women with BD in the perinatal period**

Nor has there been much investigation of the views of health professionals working with women in the perinatal period, despite a considerable amount of research into the attitudes of health professionals towards people with mental disorders generally (Lauber et al., 2006, Rao et al., 2009, MacNeela et al., 2012). Most studies on professionals' attitudes to patients with mental illness have focused on schizophrenia and/or depression. For example, Jorm et al. (1999) surveyed 2,454 psychiatrists, GPs and clinical psychologists using a vignette describing a person with schizophrenia or depression. They found that health professionals rated patients' long-term outcomes more negatively than the general public and concluded that this might be due to their better knowledge of mental disorders or it might be due to bias resulting from greater contact with patients when very ill. The few studies that have been done about care in the perinatal period have focused on professionals' attitudes to caring for women with SMI and their opinion of service needs. For example, Wan and colleagues (2008) interviewed 28 perinatal psychiatry and antenatal service workers on their views of the service needs of mothers with schizophrenia and their results highlighted the recurring themes of stigma and the need for service integration and better mental health training for midwives (this study is included in Chapter 2's review). To my knowledge, no research has been done on the views of health professionals treating women with BD in the perinatal period.

## **1.6 Study aims and objectives**

This literature review, together with the systematic review in Chapter 2, illustrates the limitations of the current evidence on the pregnancy decision making of women with severe mental illness. The lack of research on the teratogenicity of psychotropic medications and on the efficacy of alternative treatments leaves women faced with extremely complex decisions, laden with risk and apprehension. There is a particular dearth of information on the factors that influence that decision-making process for

women with bipolar disorder, the diagnosis which carries the most risk of relapse at this critical time. Nor has there been any investigation of the way psychiatrists engage with women in this position to help them make these momentous choices.

I therefore aimed to address current gaps in the evidence base through the following aims and objectives:

#### **1.6.1 PhD overarching aims:**

- i. To investigate the views of women with a history of bipolar disorder (BD) on what factors affect the decisions they need to make when considering pregnancy and childbirth, and what assistance they need to make them, whether from health professionals or other means.
- ii. To investigate the views of health professionals whom women with BD consult about pregnancy, specialist and non-specialist, on what women need at this time and how they approach advising them.
- iii. To explore with all three groups - women with BD, perinatal specialists and general psychiatrists - their views on the usefulness or otherwise of a decision aid for women with BD to use with their clinicians.

### **1.6.2 PhD objectives:**

- i. To carry out a systematic review and meta-synthesis of the qualitative literature on pregnancy and motherhood issues for women with severe mental illness.
- ii. To investigate the experiences of women with BD around pregnancy and childbirth, exploring what factors - medical, cultural, social - influence their decision to conceive.
- iii. To explore what factors influence their treatment decisions through preconception, pregnancy and the postnatal period, including around medication and potential risks to their own or their child's health.
- iv. To discover what women with BD feel they need to help them make these decisions.
- v. To investigate the views of specialist perinatal mental health professionals on their approach to advising this population and what they regard as the most important factors involved in this decision-making process.
- vi. To investigate the views of general adult psychiatrists on their approach to advising women with BD regarding pregnancy.
- vii. To discover the views of all three groups on the usefulness or otherwise of a decision-making tool for women with BD and their clinicians.

## **2 Pre-conception to parenting: motherhood for women with severe mental illness, a systematic review and meta-synthesis of the qualitative literature**

### **2.1 Introduction**

As this PhD project is chiefly concerned with the subjective experience of women with BD and discovering the factors which influence their decision-making around pregnancy and childbirth, I wanted to systematically review the qualitative literature in this area. However, because of the dearth of research focused specifically on women with bipolar disorder, I decided to widen my review beyond a diagnosis of BD to include all qualitative studies on women with severe mental illness (SMI). Very few studies are limited to participants with a single diagnosis, preferring to use the - usually undefined - term 'severe mental illness' or SMI. One of the most frequently used definitions of this oft-used category is that put forward by Graham Thornicroft's group in 2000 (Ruggeri et al., 2000). This relies on three criteria: a diagnosis of any non-organic psychosis; a duration of treatment of two years or more; and dysfunction as measured by the Global Assessment of Functioning (GAF) scale (American Psychiatric, 1987). However, most studies have not been rigorous in applying this or any other strict definition, preferring to include women with those diagnoses which are widely categorized in research as severe, that is: schizophrenia and related disorders; bipolar disorder, and major depressive disorder with psychotic symptoms. I therefore adopted this approach in this review, but have detailed the numbers of individual participants with each diagnosis where it has been specified (see table 2.1).

As limited work has been done to investigate the views of women with severe mental illness (SMI) on having children, a wide-ranging literature search was conducted to locate papers which gleaned their views on all aspects of childbirth, from preconception decision making to the potential challenges of parenting. This exercise

was valuable in order to draw together the many factors - ranging from attitudes to motherhood and fear of genetic implications to social support and stigma - which might influence women's decision-making when considering motherhood.

Pregnancy, childbirth and raising children present particular challenges to women with SMI, often exacerbating existing symptoms or acting as a trigger for a psychotic episode. This does not, however, deter the majority from becoming mothers. Indeed, Howard and colleagues (2001) found that 63% of women with psychotic disorders were mothers. There is also a sub-group of women with no history of mental illness who become psychotic in the postpartum, some of whom never have another episode. Most research in this area has either focused on the subjects' psychopathology and the potential harm to their children (Murray et al., 2003) or on service provision (Howard and Hunt, 2008, Mowbray et al., 2005). However, internationally there has been a growing awareness of the need to provide gender sensitive mental health services, e.g. 'Mainstreaming Gender and Women's Mental Health' (2003), and there is a developing literature on the experiences of mothers with severe mental illnesses including their experiences of health services. The literature on health professionals' perspectives on looking after mothers with SMI has usually focused on prescribing and risk (Lester et al., 2005, NICE, 2007) rather than their attitudes and experiences, including challenges and how to meet them. To my knowledge, there have been no meta-syntheses of the qualitative literature on pregnancy and childbirth (from preconception decision-making to views on being a mother with a mental illness) from either the perspective of women with a severe mental illness or the health professionals caring for them.

Meta-synthesis, deriving from theories developed by Noblit and Hare (1988), refers to 'interpretive translations produced from the integration or comparison of findings from qualitative studies' (Sandelowski et al., 2006). Two meta-syntheses were conducted. The first to bring together insights from qualitative studies that included the views of women with severe mental illness on pregnancy and motherhood to give a fuller account of women's perspectives on the various aspects of the experience of having children. Then a further meta-synthesis was conducted to explore the

professionals' experiences of caring for these patients, thus triangulating the data, providing deeper insights and further validation of individual themes. It is hoped that by comparing and contrasting the available data from these two perspectives, a more comprehensive account can be given of the qualitative evidence base in this area (Beck, 2002).

## **2.2 Women with SMI**

### **2.2.1 Methods**

#### **2.2.1.1 Selection Criteria**

Studies were included if they satisfied the following inclusion criteria: qualitative studies on the views of women with SMI on the subject of having children; English language papers published or in press in peer-reviewed journals with a study population including women with SMI defined as female participants 18 years and older with a psychotic disorder (schizophrenia, bipolar disorder with or without psychotic symptoms, and related disorders).

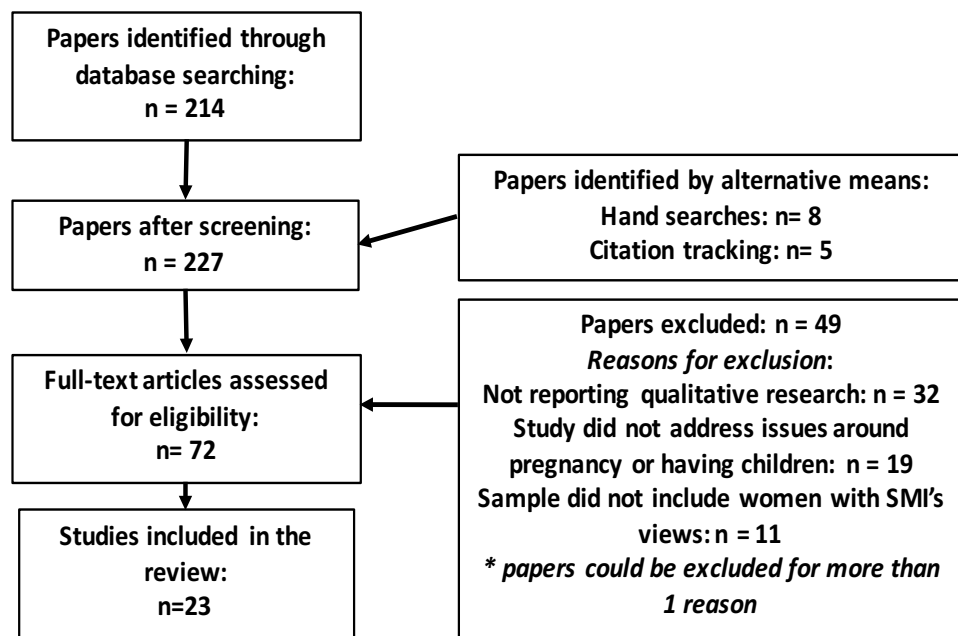
No demographic or geographic restriction was placed on sample participants or study setting. As it is good practice to be as inclusive as possible in a meta-synthesis (Walsh and Downe, 2005), papers describing the concerns of women with SMI on genetic issues and how this impacted on their views of pregnancy and motherhood could be included even if this was the only construct of relevance.

Exclusion criteria were: studies only including participants under 18 years; studies with no participants with SMI as defined above, and studies with no qualitative component (randomized controlled trials, cohort studies, case-control studies, cross-sectional studies, clinical case studies, surveys or dissertations/reports/book chapters).

### 2.2.1.2 Search strategy

The following bibliographic databases were searched from their respective start dates (given in parenthesis) to April 25, 2012: PsycINFO (1806); Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) (1946); EMBASE Classic+EMBASE (1947); Maternity and Infant Care (1971); British Nursing Index and Archive (1985); CINAHL (1982); Applied Social Services Index and Abstracts (1987); Social Service Abstracts (1979); Sociological Abstracts (1952); Social Policy and Practice (1890s). For each of the databases, an inclusive search was performed using subject headings or mesh terms, text words and key words. Search terms included: bipolar disorder, schizophrenia, severe mental illness, postpartum psychosis; pregnancy, childbirth, perinatal, antenatal, puerperal, postnatal, primipara; mother, parent, maternal; qualitative, grounded theory, focus groups. Terms were combined using the Boolean 'and' and 'or' functions and single word searches were conducted as well as subject headings to check for omissions. Searches were complemented with citation tracking and contact with ten researchers in the field (see Fig.2-1).

***Figure 2-1: Flow diagram of screened and included papers for women with SMI***



#### **2.2.1.3 Data extraction**

Relevant data were extracted from all studies using an adapted version of a standardized data extraction form (see Appendices 1 and 2) as separate forms were used for studies addressing the views of women and those addressing the views of health professionals). This was to record basic information such as sample characteristics, setting, date and form of data collection, and analytical approach. The papers were re-read to identify the first order constructs (i.e. experiences of women as reported in original studies) and second order constructs (i.e. original study author interpretations or conclusions) that they presented, and checked to confirm that the authors' interpretations were supported by the data presented in the study. At this stage the comparison across and within studies to identify and synthesize themes began.

#### **2.2.1.4 Quality appraisal**

I methodically appraised the studies by using the previously validated Critical Appraisal Skills Programme CASP (2010) as a guide. The CASP checklist was adapted to incorporate elements of the BMJ Qualitative Research Checklist (Kisely and Kendall, 2011) so that the finalised version included items assessing study context, quality of analytical methods and service user involvement. 20% of papers were independently assessed by a second reviewer (Dr. Kylee Trevillion) and I was then able to use our discussions to inform the subsequent appraisal (see checklist Fig.2-2 below):



**Figure 2-2 Quality Appraisal Checklist**

Review ID:				
Author Name:				
Paper title:				
Reviewer ID:				
<b>APPRAISAL</b>				
<p><b>Please grade the answers to each question by ticking 0, 1 or 2.</b></p> <p>Unless otherwise specified, questions should be scored as follows:</p> <p>0 – study does not meet criteria/answer question</p> <p>1 – study partially meets criteria/gives a partially satisfactory answer to the question</p> <p>2 – study fully meets criteria/gives a fully satisfactory answer to the question</p> <p>If a question is not applicable to a particular study, please mark “n/a” in the adjacent comments section.</p>				
1. The research presents clearly stated aims				
<b>Question</b>	<b>Comments</b>	<b>Score</b>		
		<b>0</b>	<b>1</b>	<b>2</b>
Is the study question focused in terms of the population studied?				
Is the study question focused in terms of the outcomes considered?				
Q1 Subtotal .....				
2. A qualitative methodology is appropriate for this research (e.g., does the research seek to interpret or illuminate the actions and/or subjective experiences of research participants?)				
<b>Question</b>	<b>Comments</b>	<b>Score</b>		
		<b>0</b>	<b>1</b>	<b>2</b>

Was a qualitative methodology appropriate?				
--	--	--	--	--

Q2 Subtotal .....

**Continue only if score on each of questions 1 and 2 is one or more**

3. The context of the research was clearly described

Question	Comments	Score		
		0	1	2
Was the context of the research clearly described?				

Q3 Subtotal .....

4. The research design was appropriate to meet the aims of the research

Question	Comments	Score		
		0	1	2
Was the research design appropriate to address the aims of the research?				

Q4 Subtotal .....

5. Was the recruitment/sampling strategy appropriate to the aims of the research?

Question	Comments	Score		
		0	1	2
Does the study have clear inclusion criteria?				
Does the study have clear exclusion criteria?				
Was the sampling strategy appropriate for the aims of the research?				
Were the subjects appropriate for the aims of the research?				
Was the study sample representative of the research setting?				

Does the study report on the level of non-participation?				
Q5 Subtotal .....				
6. Was the data collected in a way that addressed the research issue?				
Question	Comments	Score		
		0	1	2
Is the study setting appropriate to the aims of the research?				
Is the method of data collection clear?				
Is the method of data collection appropriate to the aims of the research?				
Is the process of data collection clear?				
Were study instruments piloted?				
Is data saturation discussed?				
Q6 Subtotal .....				
7. Is the data verifiable?				
	Comments	Score		
		0	1	2
	<i>N.B. Data is audio or video taped (=2), researcher makes notes during data collection (=1).</i>			
Q7 Subtotal .....				
8. Were ethical considerations appropriately considered?				
Question	Comments	Score		
		0	1	2
Did researchers obtain informed consent from all participants?				

Was data collected in a private setting?				
Was data sufficiently aggregated during presentation to ensure anonymity?				

Q8 Subtotal .....

9. Was data analysis sufficiently rigorous?

Question	Comments	Score		
		0	1	2
Is the analytical process described in detail?				
Were steps taken to identify data that was contrary to the main findings and hypotheses of the study?				
Were multiple analysts used to increase the rigour of the research?				
Does the study report on level of inter-rater reliability?				

Q9 Subtotal .....

10. Was there a clear statement of findings?

Question	Comments	Score		
		0	1	2
Does the study clearly report its findings?				

Q10 Subtotal .....

11. How valuable was the research?

Question	Comments	Score		
		0	1	2
Were service users, providers or advocates involved in the development of the study?				

Were study participants invited to receive feedback on the research?				
Were the study findings disseminated beyond the academic community?				
Did the study articulate clear recommendations for future policy and/or practice?				
Did the study articulate clear recommendations for future research?				
Q11 Subtotal .....				
<b>Total Score (out of a maximum of 62 points)</b> .....				

Papers were scored out of a total of 62, with an average of 42 achieved (scores are listed in Table 2.1). The only study falling significantly below this was Alakus et al. (2007) which scored 21 because detail on the methods employed were not available (attempts were made to reach the Australian author). It was decided this study should still be included in the review as it involved focus groups with mothers with SMI and the professionals treating them and identified pertinent themes.

#### **2.2.1.5 Analysing and synthesizing the selected studies**

Appraising quality also gave another opportunity to examine the studies and compare the constructs they had identified. Apparent contradictions and their possible resolution were also re-examined at this stage, according to the principles of Noblit and Hare's (1988) approach to synthesizing qualitative studies. Findings are juxtaposed to both identify homogeneity of themes and note discordance. This 'translation' of studies serves to identify commonalities which, in the second stage, can be synthesized to elucidate more refined meanings and concepts (Walsh and Downe, 2005). The studies were independently analysed by Prof. Louise Howard and a consensus was reached on the content of the meta-synthesis, a procedure designed to enhance reliability (Mays and Pope, 2000).

***Table 2-1 Summary of studies on views of women with severe mental illness***

<b>Studies</b>	<b>Date</b>	<b>Title</b>	<b>Country</b>	<b>Quality appraisal score</b>	<b>Methodology</b>
<b>Ackerson et al.</b> 12 outpatient mothers with SMI, psychotic or severe mood disorder	2003	Coping with the dual demands of severe mental illness and parenting	USA	42	Grounded theory + narrative history
<b>Alakus et al.</b> Focus groups of mothers with under-5s, part of "Parents with Psychosis" project	2007	The needs of parents with a mental illness who have young children: an Australian perspective on service delivery options	Australia	21	Thematic analysis
<b>Bassett et al.</b> 2 focus groups, 4 interviews with women with SMI using community rehabilitation services	1999	Parenting: experiences and feelings of parents with a mental illness	Australia	43	Thematic analysis
<b>Chernomas et al.</b> 28 outpatients 18 with schizophrenia, 10 schizo-affective disorder in focus groups	2000	Perspectives of women living with schizophrenia	Canada	37	Thematic analysis

<b>Davies and Allen</b> 11 outpatients with SMI and children, 3 with psychosis, 2 BD, 1 OCD, 5 depression	2007	Integrating “mental illness” and “motherhood”: the positive use of surveillance by health professionals. A qualitative study	UK	40	Interactional framework analysis
<b>Diaz-Caneja and Johnson</b> 22 outpatients, 8 with schizophrenia, 10 BD, 4 MDD with psychotic symptoms	2004	The views and experiences of severely mentally ill mothers: a qualitative study	UK	44	Thematic analysis
<b>Doucet et al.</b> 9 women who had been hospitalized for PP	2012	Postpartum psychosis: support needs of mothers and fathers	Canada	38	Content analysis
<b>Edwards and Timmons</b> 6 former MBU patients, 3 PPP, 1 depressive psychosis, 2 severe PND	2005	A qualitative study of stigma among women suffering from postnatal illness	UK	41	Grounded + feminist theory
<b>Engqvist et al.</b> 10 internet narratives of women with PP	2011b	Women’s experiences of postpartum psychotic episodes — analyses of narratives from the internet	Sweden	44	Content analysis
<b>Heron et al.</b> 5 women who experienced PP	2012	Experiences of recovering from PP: a service user/researcher collaboration	UK	43	Grounded analytic induction approach

<b>Khalifeh et al.</b> 18 mothers: 2 with schizophrenia, 6 BD, 10 MDD	2009	Home treatments as an alternative to hospital admission for mothers in a mental health crisis: a qualitative study	UK	53	Content analysis
<b>Meiser et al.</b> perceived genetic risk of BD: 10 euthymic Bipolar women	2005	Implications of genetic risk information in families with a high density of bipolar disorder: an exploratory study	Australia	48	Framework analysis
<b>Montgomery et al.</b> 20 outpatient mothers: 3 with schizophrenia, 4 BD, 9MDD, 4 unspecified	2006	Keeping close: mothering with serious mental illness	Canada	50	Grounded theory
<b>Montgomery et al.</b> 32 mothers with SMI inpatient and in community, Canadian Ministry of Health definition	2011	Mothers with serious mental illness: their experience of "Hitting Bottom"	Canada	41	Thematic + narrative analysis
<b>Mowbray et al.</b> 24 mothers, 15 in community. SMI according to "agency records"	1995	Parenting and the significance of children for women with a serious mental illness	USA	43	Thematic analysis



<b>Nicholson et al.</b> Focus groups with 42 mothers in community: 23 affective disorder, 8 psychotic disorder, 6 anxiety disorder, 5 other	1998	Focus on women: mothers with mental illness: 1 The competing demands of parenting and living with mental illness	USA	51	Thematic analysis
<b>Peay et al.</b> 20 women with BD 50% with children	2009	Family risk and related education and counselling needs: perceptions of adults with bipolar disorder and siblings of adults with bipolar disorder	USA	43	Thematic analysis
<b>Robertson and Lyons</b> 10 sufferers of PP	2003	Living with puerperal psychosis: a qualitative analysis	UK	47	Grounded theory
<b>Sands</b> 10 single mothers living in residential programme: 6 schizophrenia, 1 schizotypal personality disorder, 1 MDD, 1 BD, 1 unknown	1995	The parenting experience of low income single women with serious mental disorders	USA	38	Thematic analysis

<b>Savvidou et al.</b> 20 mothers, 13 living with children: 10 schizophrenia, 4 BD, 3 MDD, 2 borderline personality disorder, 1 delusional disorder	2003	Narratives about their children by mothers hospitalized on a psychiatric unit	Greece	39	Content and discourse analysis
<b>Ueno and Kamibeppu</b> 20 outpatient Japanese mothers: 13 with schizophrenia, 7 mood disorders (DSM-IV)	2008	Narratives by Japanese mothers with chronic mental illness in the Tokyo metropolitan area: their feelings toward their children and perceptions of their children's feelings	Japan	50	Grounded theory adapted for Japanese
<b>Venkataraman and Ackerson</b> 10 women with BD in community	2008	Parenting among mothers with bipolar disorder: strengths, challenges and service needs	USA	43	Grounded theory
<b>Wilson and Crowe</b> 4 women with BD in community	2009	Parenting with a diagnosis of bipolar disorder	New Zealand	34	Discourse analysis

## **2.2.2 Results of studies with women with SMI**

### **2.2.2.1 Study characteristics**

227 papers on women with SMI were initially identified, 23 studies met inclusion criteria for the meta-synthesis with a total of 355 women (see Fig. 2.1). These reflected an international perspective on the views on pregnancy and motherhood of women with SMI, with papers from 8 countries, including 6 each from the US and UK (See Table 2.1). Please note that, in the following report of results, first order constructs are quoted in italics, while second order constructs are in plain text with single quote marks.

### **2.2.2.2 Themes identified**

Nine themes were identified: Guilt; Custody loss; Concern over effect on the child; Isolation; Coping with dual identities; Stigma; Centrality of motherhood; Problems with service provision; Positive aspects of service provision. Themes have not been ranked according to relative importance or the number of times mentioned because it was not possible to deduce from such diverse studies which themes were more important to women and professionals compared to others. A second stage of synthesis was conducted which produced two overarching themes termed: Experiences of Motherhood (Table 2.2) and Experiences of Services (Table 2.3).

#### **2.2.2.2.1 Experiences of Motherhood**

##### **2.2.2.2.1.1 Guilt**

Women referred to feelings of guilt in the majority of the papers examined, but this was for a number of different reasons. Some spoke of being deeply ashamed: *"My child deserves a lot better"* (Montgomery et al., 2011). Many women, notably those

who had postpartum psychosis (PP), felt they had failed their children by being separated from them for a time as infants: *"I still have pangs of guilt that she was in there [hospital] and cared for by members of staff and not me"* (Robertson and Lyons, 2003). Many were ashamed that they "couldn't cope as a mother" (Edwards and Timmons, 2005) or that they hadn't lived up to the societal 'ideal of motherhood': *"I felt a failure, here we go again, I'm a failure as a mother"* (Davies and Allen, 2007).

Of the studies addressing parenting, several quoted women who worried about the impact of their children seeing their illness: *"I don't want them to see me in a bad way, as I saw my mother... I did not want that burden put on them"* (Diaz-Caneja and Johnson, 2004). Some mothers regretted that their illness had restricted their opportunities to provide for their children: *"Not having a job, not finishing school, not being able to get the things for them that I never had. I feel bad about that"* ((Davies and Allen, 2007). Others felt guilt that their illness-driven behaviour was bad for their children: *"I feel guilty a lot of the time because I get irritable with them"* (Wilson and Crowe, 2009). Notably, Venkataraman and Ackerson's study (2003) focusing on women with a diagnosis of bipolar disorder highlighted participants' guilt at 'setting a bad example' when manic and overspending, gambling etc.

#### **2.2.2.2.1.2 Custody loss**

Fear of custody loss was related to severe chronic illnesses, with most studies reporting it as a concern. In Ackerson's (2003) study, for example, 11 of the 12 participants were worried about losing custody; this was not without reason as 7 had lost custody of a child at some point. Bassett said this fear "permeated all they had to say" (Bassett, 1999). This fear of losing their child affected communication with care professionals, with some mothers saying they masked their symptoms because of it (Montgomery et al., 2006), while it made others reluctant to seek help (Khalifeh et al., 2009a). In Sands' study (1995), most interviewees struggled to maintain custody and were traumatized by separation, and (Savvidou et al., 2003) reported how traumatic most women found this: *"the greatest pain I've been*

*through, drugs, prison, psychiatric clinics etc., was the loss of my children*". For a number of the women with schizophrenia interviewed by Chernomas, the loss of a child was almost unbearable: *"You start to get feelings for them, and then they're gone, and you don't think you have a reason to live..."* (2000). A few papers included the comments of women who had permanently lost custody (Diaz-Caneja and Johnson, 2004, Savvidou et al., 2003), and the emotional toll this had taken: "A deep sense of loss, grief and some anger haunted the women who had lost children to child and family services. Years later these women were still struggling to process and integrate their experience of being judged an unfit mother" (Chernomas et al., 2000).

#### **2.2.2.2.1.3 Concern over the impact on the child**

This consisted of three sub-themes: genetic – that a child may have inherited her mental illness; environmental: the effects of growing up with a mother with SMI, and the impact of secondary stigma.

##### **2.2.2.2.1.3.1 Genetic**

Although only two papers focused on genetics exclusively (Meiser et al., 2005, Peay et al., 2009), this featured as a concern in several other studies (Bassett, 1999, Chernomas et al., 2000, Diaz-Caneja and Johnson, 2004, Heron et al., 2012a, Mowbray et al., 1995). In Peay's study on the perception of genetic risk among people with bipolar disorder, a large majority were concerned about their children's risk, and Meiser's interviews with the same diagnostic group found that half the women said it had affected their decision whether or not to have children. It is worth noting that in both these studies, a significant proportion had a strong family history of mental illness (in Meiser's study, all had at least two affected relatives), so their awareness of the condition's heritability would have been greater than for many women with SMI (Ackerson, 2003).

#### 2.2.2.2.1.3.2 **Environmental**

For example, concern that a mother's periodic inability to care properly for her child might cause significant developmental damage (Mowbray et al., 1995). Many were worried about the generally detrimental effect of their illness on their children (Ackerson, 2003),(Robertson and Lyons, 2003, Ueno and Kamibeppu, 2008). Some women were worried about the psychological impact of their child witnessing frightening behaviour (Diaz-Caneja and Johnson, 2004)), others by the lack of a 'normal' childhood and the burden placed upon the child to care for their mother: *"It's almost like sometimes I am the child, and he's the parent"* (Khalifeh et al., 2009a).

#### 2.2.2.2.1.3.3 **Secondary stigma**

by the child's association with a 'mad mother'. For example, Ueno and Kamibeppu (2008) say their interviewees 'worried that their children may be stigmatized as "a child of a mother with a mental illness" and quote a woman saying *"I think my child hates that I have this awful disorder"*. One parent described harassment and verbal abuse that her daughter experienced at school and in her neighbourhood, forcing them both to become reclusive. Other studies concerned with parenting also noted the impact of stigma on children and the possibility that others would reject them: *"If other mothers knew I had a mental illness, they might not allow their children to play with mine"* (Diaz-Caneja and Johnson, 2004).

#### 2.2.2.2.1.4 **Isolation**

Women returned frequently to their feelings of isolation. Sub-themes related to the damage done to social and family relationships by their illness and the difficulties of raising children alone. Many had no one to talk to (Montgomery et al., 2006), and felt very isolated (Bassett, 1999). *"Pervasive in this group [28 women with schizophrenia] was an overwhelming sense of loneliness and isolation"* (Chernomas et al., 2000). Because of their illness, they often had poor social networks and meagre financial resources, and many spoke of how much more difficult it was to

parent alone, especially when they were ill (Khalifeh et al., 2009a, Nicholson et al., 1998, Sands, 1995, Savvidou et al., 2003). These studies generally involved women with the most severe enduring illness, including a high percentage of women with schizophrenia. This contrasted with the women who had postpartum psychosis who reported strong family support networks (Doucet et al., 2012a, Heron et al., 2012a, Robertson and Lyons, 2003).

#### **2.2.2.2.1.5 Coping with dual identities**

Combining the persona of 'woman with mental illness' with that of 'mother' had both negative and positive effects on identity: *"I felt 100% female, I felt complete, a woman"* (Nicholson et al., 1998). Some studies reported the added pressure to be a 'perfect' mother: *"I had this vision of ... picture of how I would be as a mother and I didn't live up to that expectation, so it made me feel quite bad"* (Edwards and Timmons, 2005). Sometimes this is viewed positively: Nicholson et al. (1998) quotes a woman saying *"I think sometimes we make the better parents because it is so hard to be like this and we have to try twice as hard"*. Others reported that motherhood "motivated them to grow and develop" (Mowbray et al., 1995, Nicholson et al., 1998). Having interviewed and observed ten chronically mentally ill mothers in a supported residential programme, Sands (1995) suggested that they "saw childbearing and parenthood as ways to affirm their normalcy [as] parenthood is a pervasive human activity that connects one with the community".

Although identity issues were referred to in the majority of papers, it was a particular problem for women whose first experience of severe mental illness came immediately after childbirth. Heron et al. (2012a) described the shocking experience of suffering a postpartum psychosis (PP), especially with no history of mental illness, as "an affront" to one's sense of personal and social identity. Women who had suffered a PP interviewed by Robertson and Lyons (2003) described a theme of "regaining self" as they gradually recovered.

#### **2.2.2.2.1.6 Stigma**

The corrosive effects of stigma were cited in over three-quarters of the studies, exacerbating women's problems by preventing them from discussing them openly (Diaz-Caneja and Johnson, 2004); discouraging them from going out and making social contacts (Alakus et al., 2007) and making them more reluctant to seek help (Ackerson, 2003). Wilson and Crowe (2009) found that the stigma associated with a psychiatric diagnosis was reinforced by also being a parent. As Davies and Allen (2007) express it: "Women who are mothers and also users of mental health services face particular challenges of identity management because of the inherent tension between the societal ideals around the 'good mother' and social norms associated with mental illness". They feel stigmatized as women with SMI in their contact with professionals and society at large and this contributed to many women feeling "a pervasive sense of shame and guilt" (Engqvist et al., 2011).

Edwards and Timmons (2005), who focused specifically on the effect of stigma in the postnatal period, found that all of the six women interviewed had experienced stigma from others, but that they also suffered from 'self-stigma' because they saw themselves as "bad mothers". One said: *"I had this vision of how I would be as a mother and I didn't live up to that expectation, so it made me feel quite bad"*. The fact that these women felt unable "to adhere to the 'supermom' ideology further compounded their feelings of failure and the stigma they felt towards themselves" (Edwards and Timmons, 2005). In addition to this internalized stigma, the feelings of guilt were compounded by an awareness of society's stigma by association against their children (Ueno and Kamibeppu, 2008). Thus Montgomery et al. (2006) describe women's efforts to 'appear normal' for the sake of their children and, as reported above, one interviewee described her concern at the impact of stigma on her children: *"If other mothers knew I had a mental illness, they might not allow their children to play with mine"* (Diaz-Caneja and Johnson, 2004).

#### **2.2.2.2.1.7 Centrality of motherhood**

Eighteen of 23 studies highlighted the importance of being a mother to women with severe mental illness. This had negative implications when women were forced to



relinquish their mothering role due to illness as it led to feelings of failure and lowered self-esteem (Edwards and Timmons, 2005, Heron et al., 2012a, Montgomery et al., 2011). This differed somewhat between women with a disabling chronic psychotic illness and women with an episode of postpartum psychosis - a severe episode triggered by childbirth from which they had recovered. The former group often experienced a life-long struggle to cope with parenting, often alone and impoverished (Chernomas et al., 2000); (Diaz-Caneja and Johnson, 2004). The postpartum psychosis group in contrast, reported much better family and social support. Many in this group were upset that becoming a mother had not been the 'perfect' experience they had expected: *"My sisters had babies and nothing's gone wrong, it was just me..."* (Robertson and Lyons, 2003).

The vast majority of studies conveyed the positive effect of becoming a mother. The studies with the most severely ill samples, such as Chernomas et al. (2000) - 28 outpatients with schizophrenia - and Sands (1995) - 10 single mothers with SMI in a residential programme - contained particularly positive affirmations of the central role children played in these women's lives. Indeed, the latter study, which used a comparison group of well mothers attending a day-care centre, found that the women with SMI regarded being a mother as the most important thing in their lives: "in contrast with ...the day-care mothers [who] expressed more ambivalence about being a parent". "One way or another, all the mentally ill mothers said that being a mother was central to their existence, that it gave meaning and focus to their lives" (Sands, 1995)

***Table 2-2: Experiences of motherhood***

Studies	Guilt	Custody loss	Concern over impact on children	Isolation	Dual identities	Stigma	Centrality of motherhood
<b>Ackerson et al. (2003)</b> 12 outpatient mothers with SMI, psychotic or severe mood disorder	Guilty that illness affecting parenting, sometimes a danger to children	Custody concerns “an ongoing stressor” for large majority	Worried illness affected ability to parent, especially to discipline, and some concerned dangerous to their children	Combined in themes “strain of single parenthood” and “chaotic interpersonal relationships”	Independent sense of self affected by dependence on children, sometimes roles reversed	Increased reluctance to seek help, children also suffer	Greatly valued closeness to children, pride in being a mother
<b>Bassett et al. (1999)</b> 2 focus groups, 4 interviews with women with SMI using community rehabilitation services		Fear children would be removed		-		Some discriminated against by child protection, + social stigma kept them at home	

Studies	Guilt	Custody loss	Concern over impact on children	Isolation	Dual identities	Stigma	Centrality of motherhood
<b>Chernomas et al. (2000)</b> 28 outpatients 18 with schizophrenia, 10 schizo-affective disorder in focus groups		This fear “permeated all they had to say”	Fear their children will develop mental illness	Most single mothers who felt very isolated	Difficult to be yourself when scared of “saying the wrong thing” in case seen as unfit parent	Once people knew, they'd be treated differently and people would avoid them	Relationship with children extremely important
<b>Davies &amp; Allen (2007)</b> 11 outpatients with SMI and children, 3 with psychosis, 2 BD, 1 OCD, 5 depression	Felt had failed to live up to image of 'good mother'	Felt couldn't be honest about worst symptoms; 'crushed' when child removed			Dual identity' of mental patient and mother; being a 'good or 'bad' mother'	Mental illness 'not part of the idealisation of motherhood, 'felt stigmatized by health professionals'	Being forced to relinquish role of mother, feel a failure, lowers self-esteem

Studies	Guilt	Custody loss	Concern over impact on children	Isolation	Dual identities	Stigma	Centrality of motherhood
<b>Diaz-Caneja &amp; Johnson (2004)</b> 22 outpatients, 8 with schizophrenia, 10 BD, 4 MDD with psychotic symptoms	Conscious of being 'a burden to children'	Pervasive fear of losing custody 'I'd lost everything in the world'	Most feared children would become ill, for genetic or environmental reasons	Major theme was social isolation	Have to care for child and simultaneously look after their own mental health - very difficult	Most thought stigma exacerbated problems, prevented them from talking openly	20 women said children had given them a purpose in life, also increased self-esteem
<b>Doucet (in press 2012)</b> 9 women who had been hospitalized for PPP				Preferred support of family and partner as anxious about strangers	Needed 'affirmational' support that would return to 'normal'	Main problems due to ignorance of severity of PPP: confused with PND by many	Some felt denial of role as mother because baby taken away from them even temporarily
<b>Edwards &amp; Timmons (2005)</b> 6 former MBU patients, 3 PPP, 1 depressive psychosis, 2 severe PND	Guilty that they 'couldn't cope as a mother'	Half distraught that baby would be removed into care of others	Felt upset that their illness left them unable to care for child properly	This group had good family support	Worried was a bad parent: upset that didn't feel able to comfort child	All experienced stigma, made them revise their own stigmatizing views + feeling a 'bad mother' was self-stigmatising	Inability to be a 'supermom' made them feel worse

Studies	Guilt	Custody loss	Concern over impact on children	Isolation	Dual identities	Stigma	Centrality of motherhood
<b>Engqvist et al. (2011)</b> 10 internet narratives of women with PPP	8 described shame and guilt at infanticidal thoughts	Feared would lose the baby if they shared disturbing thoughts		Felt well-supported by family and partner		Pervasive sense of shame and guilt; self-stigmatising as 'failed' mothers	2 women had strong bonds with baby, even when psychotic, most felt detached
<b>Heron et al.</b> (in press 2012) 5 women who experienced PPP	All felt guilty at being a poor mother, letting child, spouse and family down		2 women spoke of worrying about 'the genetic side of things'	All stressed importance of family support, post-discharge felt isolated	Identity as probable good mother 'devastated', struggle to come to terms with being 'mental patient'	Referred to as a problem, partly as so different to PND; and for partners	Huge guilt because so wanted to care for baby - fulfilling role of 'ideal mother' very important
<b>Khalifeh et al. (2009)</b> 18 mothers: 2 with schizophrenia, 6 BD, 10 MDD	Guilt at 'failing as a mother'	Reluctant to seek parenting help due to fears of custody loss	Aware unable to care for and discipline children, also worried exposing them to distressing behaviour and burdening them		Appreciated praise from staff as concerned a 'bad' mother	Stigmatized by partners as well as community: 'He said 'you're mad, we don't want you'	Didn't want to lose children but some unhealthy dependent: 'sometimes I am the child, and he's the parent'

Studies	Guilt	Custody loss	Concern over impact on children	Isolation	Dual identities	Stigma	Centrality of motherhood
<b>Meiser et al. (2005)</b> perceived genetic risk of BD: 10 euthymic women with BD			Half said illness affected decision to have children but most would not abort affected fetus			Majority believed genetic explanation for BD is de-stigmatizing for sufferers but not socially	
<b>Montgomery et al. (2006)</b> 20 outpatient mothers: 3 with schizophrenia, 4 BD, 9MDD, 4 unspecified	Some ashamed by thoughts of hurting their children despite loving them	Masked' illness to authorities or family due to fear of custody loss	Aware of need to protect child from their illness, 'their primary responsibility'		Felt 'never good enough' as a mother, 'intensifying their efforts to appear normal'	Pressure to 'appear normal' - anxiety that not 'ideal mother' stressful	Motherhood gave life meaning, identity of 'mother' signified normalcy and security - 'our kids are our life'
<b>Montgomery et al. (2011)</b> 32 mothers with SMI inpatient and in community, Canadian Ministry of Health definition	Tremendous guilt. Many spoke of being ashamed: 'My child deserves a lot better'	Fear of custody loss when very depressed	I don't want the kids to see me suffer and worry about what effect it will have'	Needed to talk through experience of hitting 'bottom', often not able to as isolated	Stories of hitting 'bottom' illustrated 'sense of powerlessness as both a person and mother'	Felt 'isolated' and 'embarrassed' by their illness	All spoke of the importance and value of their role as mothers.

Studies	Guilt	Custody loss	Concern over impact on children	Isolation	Dual identities	Stigma	Centrality of motherhood
<b>Mowbray et al. (1995)</b> 24 mothers, 15 in community. SMI according to 'agency records'	Guilty that had 'let their children down'. 'Not the mother I had wanted to be'		Half would like to send their child to see a mental health professional as concerned how they had been affected	Single mothers felt they needed support from the children's fathers	Over 2/3 felt children 'motivated them to grow and develop'		Joy of motherhood. Most said having a child had 'motivated them to be responsible; 'I was the happiest person on the face of the earth'
<b>Nicholson et al (1998)</b> Focus groups with 42 mothers in community: 23 affective disorder, 8 psychotic disorder, 6 anxiety disorder, 5 other	Trying to balance parenting demands and illness led to stress and guilt	Constantly need to prove themselves or will lose children. Pain of losing a child never goes away: 'My heart is in chains'	Sometimes misinterpret normal problems as related to their illness: 'Because I have a mental illness, have I raised her wrong?'		Pride in being a parent 'can be a powerful motivating force', but many confront 'role-strain issues'	Undermined by societal stigma: 'People [think] we're going to abuse our children'	Unmitigated enthusiasm' for talking about their children shown in focus groups

Studies	Guilt	Custody loss	Concern over impact on children	Isolation	Dual identities	Stigma	Centrality of motherhood
<b>Peay et al. (2009)</b> 20 women with BD 50% with children			Large majority concerned about children's risk of inheriting psychiatric illness				
<b>Robertson &amp; Lyons (2003)</b> 10 sufferers of PPP	Guilt at possible effect on infants, distress to family, guilty that 'bad mother'		Worried illness may have a detrimental effect on child's development	Women described feelings of isolation and being scared	'Regaining self': women felt they had lost their minds and identity. Took time to regain self-confidence that could be good mother	stigma and lack of understanding from friends. Self-stigmatizing so more isolated	Devastated that had not lived up to 'Western ideal of motherhood' but most felt had made it up to children when recovered



Studies	Guilt	Custody loss	Concern over impact on children	Isolation	Dual identities	Stigma	Centrality of motherhood
<b>Sands (1995)</b> 10 single mothers living in residential programme:  6 schizophrenia, 1 schizotypal personality disorder, 1 MDD, 1 BD, 1 unknown		Women sensitive about their losses but needed to resolve them		Socially isolated but dependent on rehabilitation service	'Viewed selves as children': felt they were treated 'like a baby' and some expected children to look after them when older	Saw 'childbearing and parenthood as ways to affirm their normalcy'	For all, children 'central to their lives', gave them 'meaning and focus'. Some relied heavily on children for support: 6 hoped they'd take care of them
<b>Savidou et al. (2003)</b> 20 mothers, 13 living with children: 10 schizophrenia, 4 BD, 3 MDD, 2 borderline personality disorder, 1 delusional disorder		Many who lost custody in divorce spoke of their grief: 'the greatest pain I've been through... was loss of my children'	Imagined children having problems due to their mother's illness	Some isolated from children by ex-partners. Socially ostracized, relied on their family	Illness made it hard to have a mother/child relationship: 'when we need you, you are always ill...'	Greek culture sees women with SMI as 'incapable mothers'. Hard to maintain family and social relationships because of stigma	Most 'viewed children as offering primary joy to their parents' and said mothering was important to them. 'I wouldn't be alive without my child'.

Studies	Guilt	Custody loss	Concern over impact on children	Isolation	Dual identities	Stigma	Centrality of motherhood
<b>Ueno &amp; Kamibeppu (2008)</b> 20 outpatient Japanese mothers: 13 with schizophrenia, 7 mood disorders (DSM)	Remorse that their illness affected children and made them sad.	Less fear of custody loss, as own mothers cared for them and children when needed	Felt sorry for making the child distressed, for exposing them to symptoms and for stigma child faced	Less isolated as their mothers stepped in to help, but socially stigmatized	Felt need to balance 'self-care' and caring for the child	Some worried child would be stigmatized: 'My child hates that I have this awful disorder'	All expressed great love for their children: 'My child is the most important thing in my life'
<b>Venkataraman &amp; Ackerson (2008)</b> 10 women with BD in community	Felt guilty at setting a bad example when manic and overspending etc.	Prepared to renounce alcoholism or abusive relationships to keep custody	Anger and depressive behaviour had negative impact on child, and led to poor discipline		Talked about their 'positive' personality traits as strengths in parenting'		All talked positively about being a mother: 'There is no man on the face of the earth more important than my girls'

Studies	Guilt	Custody loss	Concern over impact on children	Isolation	Dual identities	Stigma	Centrality of motherhood
<b>Wilson &amp; Crowe (2009)</b> 4 women with BD in community	Self-blame: 'I feel guilty a lot of the time because I get irritable with them'		Lack of moderation can lead to undisciplined and poor parenting, felt should model self-control		Very aware of need to be 'moderate' and monitor their emotions, leads to 'problematic identity as a parent'	Felt 'judged as a bad parent' because of their diagnosis. Stigma led to 'self-surveillance'	

#### **2.2.2.2.2 Experiences of Services**

The two themes which have been combined under this heading are: Problems with service provision and Positive experiences of services (see Table 2.3).

##### **2.2.2.2.2.1 Problems with service provision**

Twenty two out of 23 studies reported problems with the provision of services, ranging from difficulties with interacting with medical staff (Wilson and Crowe, 2009, Engqvist et al., 2011, Davies and Allen, 2007)) to feeling upset by the frequent changes in personnel (Bassett, 1999). This theme also included the different treatment needs of women with postpartum psychosis, who complained of treatment delay due to misdiagnosis (Edwards and Timmons, 2005) and not being able to have their baby with them in hospital (Robertson and Lyons, 2003). Two studies cited drug side-effects as impairments to parenting which were not fully recognized by professionals (Mowbray et al., 1995) and (Savvidou et al., 2003), and some reported the need for more practical help during a crisis, such as childcare provision (Diaz-Caneja and Johnson, 2004, Nicholson et al., 1998, Venkataraman and Ackerson, 2008).

A major sub-theme in the negative experiences of service provision was the unmet need that many women identified for both information and peer support groups. The majority of researchers asked women what they felt would improve their lives in relation to becoming parents, and many suggested well-written information on discharge, especially on parenting issues (Heron et al., 2012a). Mothers who had suffered postpartum psychosis were keen for medical professionals to receive better training about the condition (Edwards and Timmons, 2005, Engqvist et al., 2011). These mothers also wanted peer support groups as they felt isolated, even from the larger group of mothers who had suffered from postnatal depression, for whom there was felt to be more support (Heron et al., 2012a). In general mothers with SMI were enthusiastic about peer support (Alakus et al., 2007, Mowbray et al., 1995, Venkataraman and Ackerson, 2008). This would give them the opportunity to

“share their experiences and obtain guidance about coping with parenting” (Diaz-Caneja and Johnson, 2004), and so could be viewed as an informal method of parenting education, which was also a popular request (Ueno and Kamibeppu, 2008, Venkataraman and Ackerson, 2008). Some expressed a preference for diagnosis-specific groups (for example, women with bipolar disorder interviewed by Venkataraman and Ackerson (2008).

#### **2.2.2.2.2 Positive experiences of services**

Many studies gave examples of positive experiences with services but these were usually at the level of individual healthcare professionals rather than the healthcare system (Bassett, 1999, Chernomas et al., 2000, Davies and Allen, 2007, Savvidou et al., 2003). An emergent sub-theme was the desire to talk regularly to someone sympathetic; when this was available it was appreciated: *“To have someone you can talk to and trust like I can with my case manager ... that makes me stable”* (quoted in (Bassett, 1999). Where specialist services were available, for example a Mother and Baby Unit (Heron et al., 2012a), rehabilitation service (Ackerson, 2003) or Women’s Crisis House (Khalifeh et al., 2009a), women were appreciative. Of the 42 women included in focus groups by Nicholson et al. (1998), the vast majority welcomed the opportunity to discuss issues with other mothers with SMI, and were disappointed that it wasn’t a regular part of recovery programmes.

***Table 2-3: Pregnancy and motherhood for women with severe mental illness: experiences of services***

<b>Studies</b>	<b>Problems with service provision</b>	<b>Positive experiences of service provision</b>
<b>Ackerson (2003)</b> 12 outpatient mothers with SMI	Delayed diagnosis, inconsistency of care, need for childcare in crises	Those accessing rehabilitation services more likely to mention professionals as supportive
<b>Alakus et al. (2007)</b> Focus groups of SMI mothers with under-5s	Need for better inter-agency communication, more information on discharge, and support groups for preschool parents	
<b>Bassett et al. (1999)</b> 2 focus groups, 4 interviews with women with SMI in community	Upset at constantly changing staff, better access to crisis help	Would benefit from contact with others in same situation, one mother appreciated having a constant case manager to talk to
<b>Chernomas et al. (2000)</b> 28 outpatients with schizophrenia in focus groups	Poor communication with professionals: reluctant to talk about parenting problems as no time	Individual good experience: "I like him as a doctor, he's very good with my schizophrenia"

<b>Studies</b>	<b>Problems with service provision</b>	<b>Positive experiences of service provision</b>
<b>Davies and Allen (2007)</b> 11 outpatients with SMI and 1 or more children	Need to “manage identity” with clinicians, felt they failed to take women with SMI seriously as “expert” mothers	Individual health visitor praised for noticing woman's needs as well as baby's, and allowing time to talk
<b>Diaz-Caneja and Johnson (2004)</b> 22 outpatients, 8 with schizophrenia, 10 BD, 4 MDD	Unmet needs for consistent support in the community, crèches for doctor's appointments, parenting support and peer groups	Generally satisfied with treatment
<b>Doucet et al. (2012)</b> 9 women who had been hospitalized for PP	Upset that put on general psychiatry ward and not allowed to see their baby. Little community support	
Edwards and Timmons (2005) 6 former MBU patients	5 women said illness severity not recognised so treatment delay	Diagnosis “label” found useful by some women
<b>Engqvist et al. (2011b)</b> 10 internet narratives of women with PP	Most women angry and not listened to by staff, who were not well informed about PPP	Minority satisfied with inpatient care

<b>Studies</b>	<b>Problems with service provision</b>	<b>Positive experiences of service provision</b>
<b>Heron et al. (2012)</b> 5 women who experienced PP	All felt should be able to have baby with them. Shock at professionals' ignorance of PPP, wanted more information and support groups	Valued specialist care if in MBU
<b>Khalifeh et al. (2009)</b> 18 mothers with SMI treated at home in a crisis	Preferred home treatment but children preferred it if mothers hospitalized	Those treated in a Crisis House preferred it to hospital or home treatment
<b>Meiser et al. (2005)</b> The authors perceived genetic risk of BD: 10 euthymic Bipolar women	Ignorance of real risks of passing on BD should be addressed	Majority satisfied that prenatal testing not offered
<b>Montgomery et al. (2006)</b> 20 mothers with severe mental illness (outpatients)	Saw professionals as not fully understanding their desire to be good mothers: "your kids will grow up fine without you"	Wanted help with parenting when ill – if available, felt they would cope better
<b>Montgomery et al. (2011)</b> 32 mothers with SMI inpatient and in community	External stressors, esp. social services, exacerbated descent into severe depression	



<b>Studies</b>	<b>Problems with service provision</b>	<b>Positive experiences of service provision</b>
<b>Mowbray et al. (1995)</b> 24 mothers with SMI, 15 in community	Services often unaware they were mothers. More help for children and practical support needed, parent support groups desirable	
<b>Nicholson et al. (1998)</b> 42 mothers with SMI in focus groups	Lack of childcare provision if need to be hospitalized – may delay help seeking	Vast majority welcomed focus group disappointed not regular
<b>Peay et al. (2009)</b> 20 women with BD 50% with children	Wanted general information on genetic risk and counselling	
<b>Robertson and Lyons (2003)</b> 10 sufferers of PPP	Some upset that treated in psychiatric unit not MBU, and wanted more information on PPP for themselves, family and partners	
<b>Sands (1995)</b> 10 single mothers living in supportive residential programme	Resentful of mental health programmes, including social rehabilitation	Appreciated stability of rehabilitation programme allowing them to keep custody of children

<b>Studies</b>	<b>Problems with service provision</b>	<b>Positive experiences of service provision</b>
<b>Savidou et al. (2003)</b> 20 Greek mothers with SMI, 13 living with children	Tried to conceal illness to avoid custody loss, most felt their opinions ignored in decisions about the children	Social services helped them to keep in contact with children
<b>Ueno and Kamibeppu (2008)</b> 20 Japanese mothers with SMI	Need for parenting education	
<b>Venkataraman and Ackerson (2008)</b> 10 women with BD in community	Wanted more crisis help for themselves and children, help with parenting and peer support groups	
<b>Wilson and Crowe (2009)</b> 4 women with BD in community	Felt professionals judging them as inadequate parents: "I felt like he was blaming me — that ... I had deliberately ruined ... this child"	

## **2.3 The views of health professionals on the pregnancy and childbirth issues of women with severe mental illness**

### **2.3.1 Methods**

#### **2.3.1.1 Selection criteria**

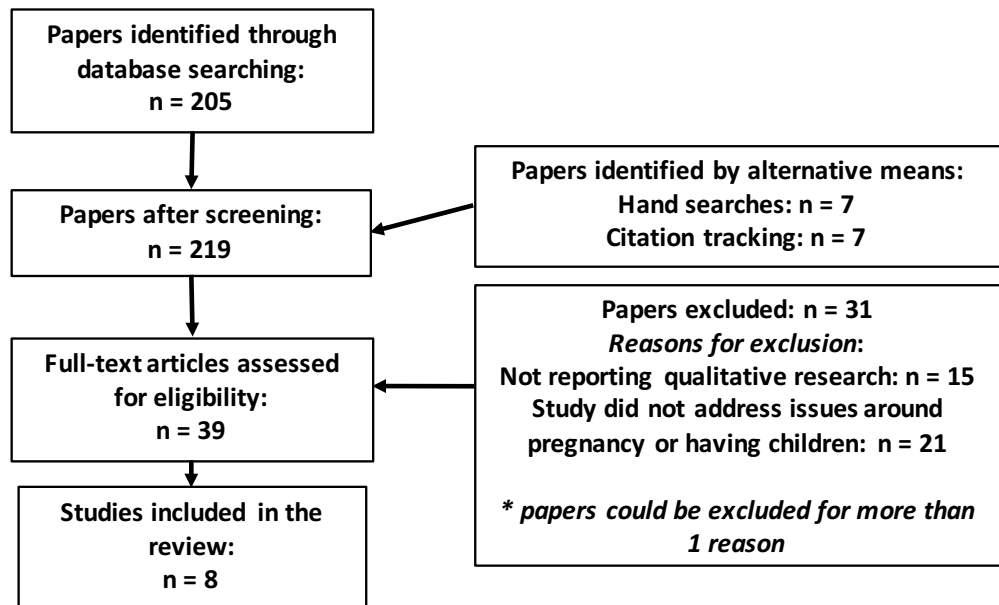
**Inclusion criteria:** qualitative studies on the views of health professionals caring for women with SMI in the perinatal period; English language papers published or in press in peer-reviewed journals with a study population including healthcare professionals caring for women with SMI in the perinatal period.

**Exclusion criteria were:** studies with no qualitative component (randomized controlled trials, cohort studies, case-control studies, cross-sectional studies, clinical case studies, surveys or dissertations/reports/book chapters).

#### **2.3.1.2 Search strategy**

Using the same databases, a separate search was conducted to identify studies examining the experience of health professionals caring for pregnant women or mothers with SMI. Additional search terms included: health professionals, medical professionals, clinicians, doctors, psychiatrist, nurses, midwives, perinatal psychiatric workers, antenatal healthcare workers (Fig. 2-3).

***Figure 2-3 Flow diagram of screened and included papers for health professionals***



### **2.3.1.3 Study quality appraisal**

As for the women's studies, papers were appraised using the quality appraisal checklist described at 2.2.1.4 (see Appendix 2). Papers were scored out of a total of 62 and scores are listed in Table 2.4.

### **2.3.1.4 Analysis**

The same methods of qualitative analysis and meta-synthesis were employed as described for the studies on the views of women with SMI (see Fig 2-3).

## **2.3.2 Results**

### **2.3.2.1 Study characteristics**

Eight papers (from an original search of 218) were located which reported the views of 143 health professionals on the pregnancy and childbirth issues affecting women with severe mental illness (see Fig. 2.2). These figures include one paper, Nicholson et al.

(1998), which reported results from both groups. Details of these papers are given in (Table 2.4). Of note however, is that four of these papers were by Engqvist and colleagues in Sweden focusing on health professionals caring for women with postpartum psychosis. Two of these studies used the same dataset to describe the experiences of psychiatric nurses and the later two used another dataset to describe the experiences of psychiatrists. One of the two UK papers described perinatal psychiatric and antenatal workers (see Table 2.4 for details) caring for women with SMI (Wan et al., 2008), and the other addressed the attitudes of mental health nurses towards severe perinatal mental illness (McConachie and Whitford, 2009). The American paper reported on focus groups with psychiatric case managers as well as groups of mothers with SMI, described earlier (Nicholson et al., 1998).

***Table 2-4: The views of health professionals caring for women with severe mental illness: summary of papers***

Author	Date	Title	Quality appraisal score	Number of participants	Method
Engqvist et al. (Sweden)	2007	Strategies in caring for women with postpartum psychosis — an interview study with psychiatric nurses	42	10 psychiatric nurses	Interviews
Engqvist et al. (Sweden)	2009	Psychiatric nurses' descriptions of women with psychosis occurring postpartum and the nurses' responses — an exploratory study in Sweden	40	10 psychiatric nurses	Interviews
Engqvist et al. (Sweden)	2010	Nurses — psychiatrists' main collaborators when treating women with postpartum psychosis	52	9 psychiatrists	Interviews
Engqvist et al. (Sweden)	2011a	Comprehensive Treatment of Women with Postpartum Psychosis across Health Care Systems from Swedish Psychiatrists' Perspectives	51	9 psychiatrists	Interviews

Author	Date	Title	Quality appraisal score	Number of participants	Method
<b>Maddocks et al. (UK)</b>	2010	A phenomenological exploration of the lived experience of mental health nurses who care for clients with enduring mental health problems who are parents	45	6 psychiatric nurses	Interviews
<b>McConachie and Whitford (UK)</b>	2009	Mental health nurses' attitudes towards severe perinatal mental illness	48	16 psychiatric nurses	3 focus groups
<b>Nicholson et al. (USA)</b>	1998	Focus on women: mothers with mental illness: The competing demands of parenting and living with mental illness	51	55 Mental Health Case Managers	5 focus groups
<b>Wan et al. (UK)</b>	2008	The service needs of mothers with schizophrenia: a qualitative study of perinatal psychiatric and antenatal workers	48	28:15 midwives, 7 Reg. Mental Nurses, 3 MBU nursery nurses, 1 antenatal manager, 1 obstetrician, 1 psychiatrist	Interviews

### **2.3.2.2 Themes identified from meta-synthesis of Health professionals' views**

Table 2.5 displays the five themes which emerged from a synthesis of these papers:

*Anxiety; Additional responsibility; Stigma; Need for education; Integration of services.*

These were further synthesized into two superordinate themes: *Experience of professionals*, comprising the first three, and *Views on service provision*, combining the latter two.

#### **2.3.2.2.1 Experience of professionals**

##### **2.3.2.2.1.1 Discomfort**

Two themes that emerged under the heading of 'experience' were *Anxiety* and *Additional Responsibility* which overlapped to the extent that they have been combined under the superordinate theme of *Discomfort*.

##### **2.3.2.2.1.2 Anxiety**

McConachie and Whitford (2009) found that general psychiatric nurses "had little experience and felt uneasy working with women who had a severe mental illness in the perinatal period" and were "frightened" of looking after a baby. "*I think it is stressful ...I feel responsible...my worries and anxieties go up right away*" (Community nurse). Similarly, Wan et al. (2008) revealed the anxiety of midwives when dealing with women with schizophrenia as they felt inadequately trained for the task: "*When somebody says schizophrenia, especially in midwifery, people get frightened because they think they're symptomatic ...I think we need more awareness sessions for midwifery*" (registered mental nurse working in the antenatal clinic). The psychiatrists interviewed by Engqvist (2011) felt burdened by a feeling of "great responsibility" for both mother and child when making decisions. The psychiatric nurses in the 2009 Swedish study spoke of the "strong emotions" they felt treating women with postpartum psychosis, including "sadness, sympathy, empathy, compassion,



discomfort, anger, anxiety and happiness”. One nurse said: *“Often the women have a very extroverted chaotic behaviour, hard to work with, creating much anxiety in both me and others”*. Several were anxious about the responsibility of keeping the women and their babies safe, and two nurses described being angry with a mother who drowned her baby. Engqvist and colleagues suggest educators should address this problem as these negatively charged emotions “could interfere with providing compassionate and effective nursing care”.

#### **2.3.2.2.1.3 Additional responsibility**

For five of the studies analysed, the difference for staff was the need to care for an infant as well as an adult patient; however, the converse applied for the midwives in Wan et al. (2008) who found it challenging to care for a new mother who was also mentally ill. For example, asked to recommend an intervention for mothers with schizophrenia, a midwife responded: *“I don’t know enough about mental health ...I think generally people are more sympathetic to people that have a physical illness ...as opposed to mental illness”*. In the two Swedish papers analysing interviews with nurses experienced in caring for women with postpartum psychosis, the nurses found that ‘they need to address the relationship between the woman and her child ... [the nurse] becomes a model for the patient of how to care for her baby ... *“and by so doing I try to encourage this type of contact”* (nurse) (Engqvist et al., 2007). The psychiatrists (Engqvist, 2011) describe being ‘more involved with these women compared with other patients’ *“because there is so much at stake. It is not just a woman with psychosis but also her child and its earliest experiences which are so extremely important”*.

Nicholson et al. (1998) reported that case managers ‘expressed a great deal of concern for the children of mothers with SMI, and felt that the women did not have enough resources to help them cope. This was echoed by psychiatric nurses in the Maddocks study (2010): *“I used to find it quite difficult because ... you want to support them but you have to think about the child, you have to think about their safety, their future and their emotional needs as well”*. Psychiatric nurses questioned on their feelings about

caring for women with SMI in the perinatal period saw this as very challenging (McConachie and Whitford (2009). They were 'frightened about looking after babies' and felt insufficiently trained: *"No, I don't do mothers and babies, no seriously I know my limitations, I would not take that on. I would feel very uncomfortable"*.

#### **2.3.2.2.1.4 Stigma**

All studies referred to stigma as an issue. Wan et al. (2008) described "perceived ignorance and social stigma attached to mental illness" as one of two overarching themes that recurred across topics and across the range of participant occupations. Nicholson et al. (1998) quote a case manager saying: *"It is always the stigma of being mentally ill. When [the mothers] go to the hospital to give birth, people immediately assume they cannot care for the child."* This stigmatizing attitude extended to healthcare workers and "sometimes led to negative preconceptions among workers concerning the abilities of mothers with SMI to be 'good' mothers, and to their negative treatment by workers". A psychiatric nurse commented: *"I think, on behalf of services which have given support, there's ignorance about mental illness and how mental illness works"*. Similarly, all three focus groups reported by McConachie and Whitford (2009) discussed the stigmatization of a mental health referral. They also raised the problem of women manipulating their scores on the Edinburgh Postnatal Depression Scale to avoid being seen as a 'bad mother' and losing custody. Psychiatrists in Engqvist et al. (2011) felt extra pressure when deciding on a diagnosis of postpartum psychosis "as this disorder can be stigmatizing". Thus medical professionals are aware of the stigmatization suffered by mothers with SMI, and are also aware of it occurring among health workers: *"When somebody says schizophrenia, especially in midwifery, people get frightened ...we need more awareness sessions for midwifery"* (psychiatric nurse quoted in Wan et al. (2008).

### **2.3.2.2.2 Views on service provision**

#### **2.3.2.2.2.1 Need for education**

As may be seen from the quote above, some health professionals saw a need for education as a means of tackling stigma, but other studies emphasised the other areas training could address. The psychiatric nurses in McConachie and Whitford's (2009) study felt they needed more specialized training to deal with mothers and babies: *"Caring for the women is alright – it is the babies I don't like (lots of laughter), it certainly poses a challenge. Assessing how she is caring for the child ... we're not qualified for that"*. The nurses interviewed by Maddocks (2010) also said they felt ill-equipped to assess their clients' parenting capacity: *"I wouldn't know what to look for"*. Conversely, the focus groups in Wan et al. (2008) called for more psychiatric training for midwives as well as parenting education for patients, and a psychiatrist quoted in Engqvist et al. (2010) emphasized that nurses caring for women with postpartum psychosis needed to be knowledgeable about the disorder: *"this is not routine care, the nurses must give top care to these patients."* Two other Swedish studies (Engqvist et al., 2009, Engqvist, 2011) brought out the theme of education as a means of addressing the anxiety suffered by professionals treating women with postpartum psychosis: *"It is important to address these issues in nursing education and in clinical practice"* (Engqvist et al., 2009). For the psychiatrists interviewed in the 2011 study, peer supervision or support was suggested, and some American case managers *"suggested they themselves were not provided with adequate support for dealing with these issues"* and were keen to join with their peers in a focus group discussion (Nicholson et al., 1998).

#### **2.3.2.2.2.2 Integration of services**

This theme echoes some of the comments about disconnected services made by women with SMI under the theme *Problems with service provision*: *"It's good networking that we require with the services – primary care, the GP and if there's been a CPN involved and the health visitor and the midwife"* (antenatal manager

quoted in Wan et al. (2008). Psychiatric nurses (McConachie and Whitford, 2009) also identified problems with sharing responsibility: “There isn’t any information sharing ... unless they’re looking for us to do something” (community nurse). This was echoed in Maddocks et al. (2010): “social workers for children might not necessarily have that great an understanding of adult mental health and vice versa. There needs to be common ground”. The Swedish studies also emphasized the need for the whole treatment team to collaborate: “I think that it is possible to cooperate for a patient’s sake with all the different staff and the varied areas of expertise” (Engqvist et al., 2007). They also underscored the importance of including the family in the treatment plan and discharge planning process (Engqvist, 2011).

***Table 2-5: Views of health professionals caring for women with SMI: themes***

Studies	Experiences of Professionals			Views on Service Provision	
	Anxiety	Discomfort	Stigma	Need for Education	Integration of services
<b>Engqvist et al. (2007)</b> 10 psychiatric nurses interviewed (9 female 1 male)		Need to care for baby too + provide 'a model' for mother, + educate family about postpartum psychosis			Whole treatment team needs to co-operate. Nurse acts as link, coordinating after-care
<b>Engqvist et al. (2009)</b> 9 psychiatric nurses interviewed (8 female 1 male)	8 described having 'strong responses' including 'discomfort, anger and anxiety'	Need to foster mother's relationship with baby, many women 'disconnected' from child. Feel 'terrific burden and sense of responsibility'		Nurse education needed to address negative feelings towards mothers with SMI, help them develop strategies to cope	
<b>Engqvist et al. (2010)</b> 9 psychiatrists interviewed (5 male 4 female)	Psychiatrists 'expressed doubts concerning their own practice, and insecurity about making the best treatment decisions'	Believed nurses needed to be able to assess interaction between mother and her child		This is not routine care' nurses need good knowledge base of PPP	Outpatient clinic team follow up for 6-12 months + collaborate with childcare centre Recognise importance of involving family

Studies	Experiences of Professionals			Views on Service Provision	
	Discomfort			Need for Education	Integration of services
	Anxiety	Added Responsibility	Stigma		
<b>Engqvist et al. (2011)</b> 9 psychiatrists interviewed (5 male 4 female)	More involved: focused on 'protecting women with PP from suicide and infanticide'	Concern for baby's safety + risk of suicide - feel very responsible as 'so much at stake'	Keen to give accurate diagnosis 'as this diagnosis can be stigmatizing'	Services should consider providing support and/or peer supervision for professionals in this field	Underscored importance of including family in treatment plan and discharge planning process
<b>Maddocks et al. (2010)</b> 6 psychiatric nurses interviewed (gender unspecified)	Unsure how involved with patients as parents: 'I think a lot of nurses are frightened of it'	Aware of child protection responsibilities: 'you have to think about [the child's] safety'		Worried about their lack of knowledge and training regarding children: 'I'm not confident at it because I'm not trained in it'	Numerous references made to the importance of liaising with other agencies: 'We need closer working relationships with social services'

Studies	Experiences of Professionals			Views on Service Provision	
	Discomfort			Need for Education	Integration of services
	Anxiety	Added Responsibility	Stigma		
<b>McConachie &amp; Whitford (2009)</b> 16 psychiatric nurses in 3 focus groups (14 female 2 male)	Many felt very uneasy working with women in the perinatal period; 'they were frightened about looking after babies'	Need more training, better integration of services: frustrated at lack of collaboration with other services	The stigmatization of a mental health referral was discussed in all groups women might manipulate EPDS score to avoid losing custody because viewed as 'poor mother'	Felt needed more specialized training, especially to care for baby: 'Assessing how she is caring for the child...we're not qualified for that'	Identified problems of accountability and sharing responsibility: frustrated at 'lack of communication from other professionals'
<b>Nicholson et al. (1998)</b> 55 Mental Health Case Managers in 5 focus groups	Case managers 'struggled' with clients' multiple problems + 'expressed a great deal of concern' for the children of mothers with SMI	Managers spoke of additional concern for children involved and of the lack of resources to help the women cope	Case manager: "It is always the stigma of being mentally ill. When [the mothers] go to the hospital to give birth, people immediately assume they cannot care for the child"	Some suggested they themselves needed more support, requested training sessions	Need for more support services: "I've seen a lot of mothers go into crisis, needing hospitalizations and debating which should come first, their mental health or child care, because they had no-one in the

Studies	Experiences of Professionals			Views on Service Provision	
	Discomfort			Need for Education	Integration of services
	Anxiety	Added Responsibility	Stigma		
<b>Wan et al. (2008)</b> 28: 15 midwives, 7 Reg. Mental Nurses, 3 MBU nursery nurses, 1 antenatal manager, 1 obstetrician, 1 psychiatrist	Midwives anxious that not trained to recognise or nurse psychiatric patients	Aware of need to monitor patients' mental health constantly: 'I think we fail them postnatally...because I think the emphasis does go on the baby'	Perceived ignorance and stigma attached to mental illness, including among healthcare workers, identified as major reason for poor postpartum care	More psychiatric education for midwives requested by midwives themselves and need for parenting training for patients	Need 'integration of services and continuity of support', Most felt women with schizophrenia received 'insufficient postnatal support'
					community that could help them"



## **2.4 Discussion**

### **2.4.1 Main findings**

#### **2.4.1.1 Experiences of women with SMI**

I found that, despite the heterogeneity of samples and methods in these studies, it was clear that the experience of motherhood evokes powerful emotions for women with severe mental illness (SMI) regardless of diagnosis or socio-cultural context. Indeed there is some evidence (Sands, 1995) that women with SMI valued motherhood more highly than other women, perhaps because they had little else positive in their lives, or because the fear of having them taken away made them appreciate them all the more. Thus although no studies reported data related specifically to pregnancy, the vast majority of studies (19 of 23) emphasized the importance women attached to becoming mothers, both in terms of their own self-esteem, and in the way that their children were central to their existence, conferring benefits such as “love, purpose, identity and support” (Chernomas et al., 2000). However, for many women, being a parent with a major mental illness is associated with stigma, guilt, isolation and concerns over the impact of illness on their children or the possibility of custody loss: a pervasive anxiety for many women in these studies. Consultations with health professionals for pre-conception advice, antenatal care or mental healthcare while parenting may therefore be influenced by these underlying concerns even if they are not disclosed during interviews (Davies and Allen, 2007).

Stigma was a particularly prominent theme which may impact on access to healthcare. Women described feeling stigmatized and felt that society’s negative attitudes and assumptions impacted on professionals’ views of their parenting abilities and the potential loss of custody of children (Bassett, 1999, Diaz-Caneja and Johnson, 2004, Montgomery et al., 2006, Nicholson et al., 2007). The stigma associated with mental illness was exacerbated by becoming a parent as women felt doubly stigmatized - by

some health professionals as well as society generally - because their capacity to be 'a good mother' was automatically doubted (Chernomas et al., 2000, Davies and Allen, 2007, Edwards and Timmons, 2005, Khalifeh et al., 2009a, Wilson and Crowe, 2009). This concurs with a recent quantitative survey which found that people with a mental illness rated 'being seen as a bad parent' as the second most important barrier to seeking psychiatric care (Clement, 2012). This recurring theme overlapped with the consciousness of having 'dual identities' as a mentally ill woman who was socially stigmatized and in need of the State's help, while at the same time trying to fulfil the idealized role of extremely competent, nurturing and selfless mother.

Within the overarching theme of Experiences of Services, prominent sub-themes were the lack of continuity of care and the need for childcare provision, especially in a crisis, confirming earlier findings from surveys. An unmet need for information was also evident as in other types of studies (Howard and Hunt, 2008), and a need for peer support, which might prove particularly helpful to this population, isolated by both the stigma of mental illness and the need to care for an infant full-time. Unfortunately, there is a scarcity of good quality research on whether such support could improve social networks and childcare.

The singular experience of women suffering from PP was evident in several themes. For women who had never experienced mental illness before and had anticipated a 'perfect' birth, the chasm between expectation and reality was hard to bear. Thus comments on Guilt, the Centrality of Motherhood and Coping with Dual Identities were plentiful from this group of women, whereas they were far less likely to refer to suffering from isolation as they generally reported strong support from partners and family members (Doucet et al. 2012; Heron et al. 2012). This contrasted with the majority of studies where there was no mention of fathers or partners except in the context of their absence. This is similarly found in other studies, especially those looking at schizophrenia (Bosanac et al., 2003). In this review, excluding the PP subgroup, a large proportion of participants were single (e.g. Sands' paper on 10 single mothers living in a residential programme). The preponderance of single mothers also partly explains the prominence of concerns about custody loss and isolation, for

example Mowbray highlighted that single mothers ‘felt they needed support from the children’s fathers’ (Mowbray et al. 1995) and some of the mothers interviewed by Savvidou (2003) reported feeling deliberately isolated from their children by fathers.”

#### **2.4.1.2 Experiences of Health professionals treating women with SMI**

Health professionals’ views overlapped with women’s views in terms of their consciousness of stigma. Non-psychiatrically trained groups, particularly midwives, acknowledged that ignorance and stigma affected the poor postpartum care given to women with SMI (Wan et al., 2008). They concluded the best way to tackle this problem would be to provide more education in mental health. Parenting support was suggested by both women with SMI and professionals caring for them, and so has potential as an intervention, though more research needs to be done on the efficacy of such interventions for women with SMI (David et al., 2011).

The challenges of treating severely ill women together with newborns, and the safety issues that presents, came through strongly in the health professional theme of Anxiety as well as in some professionals’ requests for more training to help them cope more effectively (Engqvist, 2011, McConachie and Whitford, 2009). Other suggestions from professionals included peer support and supervision for perinatal psychiatrists (Engqvist, 2011), and more psychiatric education for midwives (Wan et al., 2008). This desire for more specialist training for the professionals was echoed in some of the patients’ interviews (Engqvist et al., 2011, Heron et al., 2012a). This is pertinent to the current international debate over whether perinatal mental health services should be specialist and whether women should be treated in specialised mother and baby units as occurs, albeit sporadically, in the UK. The results of this review support the assertion of the National Institute for Health and Clinical Excellence that staff should receive training on mental disorders and women with SMI should normally be admitted to a specialist mother and baby unit (NICE., 2014). Internationally there is increasing awareness of the special needs of women with mental illness in the perinatal period, as evidenced by guidelines on the subject such as SIGN in Scotland (SIGN, 2012) and ‘Beyond Blue’ in Australia (beyondblue, 2011).

### **2.4.2 Evidence gaps**

This review highlights notable gaps in the literature, for example, the absence of research on preconception views on motherhood among women with SMI, and how mentally ill women who lose their children can be supported by services (Stanley and Penhale, 1999). Some research has been done on the characteristics of women with SMI who lose custody (Hollingsworth, 2004) but little has been done on women's own experience of separation from their children, the effect it might have on their illness (Dipple et al., 2002) and how professionals should acknowledge this and respond appropriately (Sands, 2004). The efficacy of parenting interventions for women with SMI and the usefulness of peer support for this group would also benefit from more exploration (Nicholson et al., 1993).

Since publishing this review, a small UK pilot study employing service user researchers asked 12 women with SMI (including 8 with BD) to give their views on making decisions about psychotropic medication during pregnancy (Stevenson et al., 2016). They concluded that women felt a need to rely on their own experience and common sense as professionals advising them only had limited information. Recently, Dutch researchers have published a study interviewing 15 women with BD about their thoughts on family planning and pregnancy (Stevens et al., 2017). Ten women wanted to have children, one had decided not to and four were still in doubt. The main themes identified were concerns over the heritability of BD, medication worries, doubts regarding mothering capability and the need for support from partner, family and health professionals. Researchers concluded that family planning is an essential topic in the treatment of every woman with BD of childbearing age, and professionals should encourage women to express their thoughts on the subject. Interestingly, Dutch women are able to access a POP team (the Dutch model for collaboration between Paediatric, Obstetric and Psychiatric care) which offers preconception counselling for women with psychiatric problems.

Noonan and colleagues (2017) have also conducted an integrative review of midwives' perceptions of caring for women who experience perinatal mental health problems. They included 15 quantitative, 6 qualitative and one mixed methods study, with two

overarching themes emerging relating to personal and professional engagement. Within *personal engagement* four sub-themes are represented: knowledge, skills, decision-making and attitude. There are also four themes under *professional engagement*: continuous professional development, organisation of care, referral, and support. Like the current study, they found problems with stigma and lack of knowledge which needed to be addressed by providing more training in this area and proposed that continuous professional development opportunities were needed to challenge attitudes to perinatal mental health and improve communication and assessment skills among midwives. They further concluded that such training needed to be supported by appropriate referral pathways and support systems to have any benefit.

### **2.4.3 Limitations**

The studies reviewed were heterogeneous in samples, methodologies and context. As is usual in qualitative research, many of the studies have small sample sizes and several did not interview a representative mix of women. Therefore it was important to assess both the methodological and reporting quality of studies to substantiate any conclusions drawn from the meta-synthesis. If the majority of studies in the review were found to be of poor quality this would seriously undermine the validity of the meta-synthesis' results. Hence all studies were appraised for quality using a checklist derived from the Critical Appraisal Skills Programme (CASP) 2010 and the BMJ Qualitative Research Checklist (Kisely and Kendall 2011) (see Fig 2.2). This framework facilitated a consistent approach and an average score of 42 out of 62 was recorded which indicated a good standard of methodology which met acceptable ethical standards.

The majority of studies did not differentiate between diagnoses when reporting results so it was not possible to distinguish between the views of women with different conditions. However the two papers exclusively about bipolar disorder and parenting revealed the development of a heightened awareness of the need to self-monitor moods (Wilson and Crowe, 2009), and the possible advantages of hypomanic energy

when parenting (Venkataraman and Ackerson, 2008). More research is needed to determine whether specific diagnoses present particular problems in the perinatal period and early years of motherhood.

#### **2.4.4 Conclusions and implications**

The needs of women with SMI when they have children has tended to be overlooked by professionals (Howard, 2006, Krumm and Becker, 2006), but there is now a growing literature on their views which is synthesized here. This is the first systematic review to give an overview of the qualitative literature in the area of women's mental illness in relation to having children from pre-conception to parenting. Despite the heterogeneity of the studies included here, this review highlights the complexity of the challenges facing women with SMI when they have children and the ways in which issues such as stigma and fear of custody loss serve as barriers to the establishment of a positive therapeutic relationship with health professionals. Research into possible interventions such as preconception counselling, parenting programmes and peer support is needed. The results emphasize the central importance women with SMI assign to motherhood (David et al., 2011, Dipple et al., 2002), a fact that should not be underestimated when caring for this population. This review also highlights the level of anxiety health professionals from different disciplines experience when caring for women with SMI in the perinatal period, and some of the interventions, such as improved specialist training and workplace peer support, which might address it.

[This systematic review and meta-analysis has been published: Dolman, C., Jones, I. and Howard, L.M., 2013. *Pre-conception to parenting: a systematic review and meta-synthesis of the qualitative literature on motherhood for women with severe mental illness*. Archives of women's mental health, 16(3), pp.173-196.]

[Copy attached in back of bound version's folder].

### **3 A qualitative study of the views of women with BD on decision-making around pregnancy and childbirth**

#### **3.1 Introduction**

Following the review of the qualitative literature on motherhood for women with severe mental illness reported in Chapter 2 and the lack of research aimed specifically at women with BD concerning this topic, I decided to conduct a more in-depth exploration of the views of women with BD on pregnancy and childbirth decision making. Understanding how decisions are reached regarding pregnancy and identifying the barriers which prevent women from accessing the help with decision making they need, could inform the development of interventions for these women and their partners to aid this difficult process, and might influence the development of services that would better serve their needs.

#### **3.2 Methods**

This study employed a qualitative design, chosen because this will enable a thorough exploration of the key research questions whilst providing prospective mothers with BD the opportunity to explain their feelings and views in their own words. Such an approach is advocated in areas such as these which have received little research attention (Mays and Pope, 1995). Qualitative methods are therefore ideal to explore this area as participants are able to spontaneously voice issues which matter to them - issues which may not have occurred to the researchers and hence would not have emerged using a more prescriptive approach (Hays and Singh, 2011). This study had two arms: firstly, a series of semi-structured interviews with women with BD who were considering pregnancy, already pregnant or previously pregnant, conducted by myself as a service user researcher. Data was then collected from online contributions from women with BD posted on the internet forum of the charity Bipolar UK in response to

a research request. Using two or more different methods of data collection in this way is termed triangulation by qualitative researchers. Triangulation describes ‘the combination of different methods, study groups, local and temporal settings’ in dealing with a phenomenon (Flick, 2014). In this way it can be used as a strategy to improve the quality of qualitative research and enhance the validity of results. The methods employed in each arm will be described in turn.

### **3.2.1 Methods employed in the interview arm of the study**

#### **3.2.1.1 Design**

Individual interviews were semi-structured, allowing participants to express their views openly (DiCicco-Bloom and Crabtree, 2006). A topic guide was devised and piloted with four women and was reviewed after each interview, using an iterative approach (Srivastava and Hopwood, 2009).

#### **3.2.1.2 Ethical Approval**

This study received ethical approval from Camden & Islington Research Ethics Committee (11/LO/1469).

#### **3.2.1.3 Development of Interview Topic Guides**

A topic guide was developed to allow the researcher and participant to engage in a dialogue whereby questions follow participant’s responses and the researcher was able to explore important areas that arose. The guide was based on the literature on women with SMI and their attitudes to childbirth and parenting examined in Chapter 2 and my own experience, as a mother myself and in my work through Bipolar UK, of what issues concerned women in this situation. It was deliberately general and open-ended so that the women participating had the opportunity to spontaneously suggest factors which they saw as important when making decisions on this subject. This interview schedule was then piloted and reviewed, after which additional questions



were added to glean more detail on participants' experience of their illness and how they had come to be given a diagnosis of BD. This proved useful in two ways: a) it provided useful context for their thought processes when they came to think about pregnancy and b) it provided a useful 'warm-up' for participants to feel more comfortable and relaxed talking to me about private matters (because of the stigma against mental illness, many women I interviewed had not discussed their illness or their thoughts about pregnancy outside of close family so some were understandably hesitant at first). Figure 3.1 below details the topic guide.

**Figure 3-1 Interview topic guide for women with BD (considering pregnancy)**

I want to ask you about your experience thinking about pregnancy and how it might affect your bipolar disorder, or vice versa. I'm particularly interested in this subject because I have bipolar myself and I have had 2 children, and I know that many women in our situation think a lot about what might happen when we have children. If it's okay with you, I'd like to hear what your thoughts are on the matter and then afterwards if you want I can give you some information leaflets that you might find useful and we can chat about it more generally.

Can I ask you a bit about your illness first – when you were first diagnosed and how it affects you? How have your family been about it? What about your partner?

I understand you are considering having children? If so, what factors are important to you when thinking about it?

*What is the significance of your bipolar disorder in your decision-making?*

What, for you, were the most important considerations?

Do you think the fact that you have bipolar will make any difference to any children you might have?

Have you discussed this matter with your partner, family and/or friends?

*If no, is there a reason for that? If yes, how did they react?*

*[What is the attitude to mental illness in your community?]*

*[What is the attitude to having children?]*

Have you ever discussed this matter with any medical professionals?

*If so, how did that go?*

How much do you know about having a baby as a woman with bipolar?

Do you feel you know what you need to know?

*If no, what do you think would be helpful?*

When you discussed it with the doctor, how did you feel about the conversation?

*Did you make the decision in the way you wanted – with their help for instance?*

How you would like it to be?

*how much help would you want from your doctor, for instance? Do you see it as a big responsibility or do you prefer to make the decisions yourself?*

*What about over medication?*

What sort of information do you think you need to know, and how do you think that would be best delivered? Would a decision aid be helpful? In what format?

Is there anything you think is relevant about these issues which we haven't discussed?

As a result of the piloting process, I realized it would be helpful to produce three slightly different versions of the topic guide for women who were a) considering pregnancy (Fig 3-1), b) those who were pregnant and c) those who had given birth (see Appendices 3 and 4). This was partly to account for their different circumstances and to minimize the possibility that women already pregnant or having just given birth might be upset by questions about the possible detrimental effects of their illness on their child.

#### **3.2.1.4 Characteristics questionnaire developed**

A diagnostic and socio-demographic questionnaire (adapted from other studies) was used to gather information about participants (see Appendix 5). This collected data on age; relationship status; ethnicity; employment and education history; partner's employment and education details, and who lived in their household. It also enquired about state of pregnancy, if pregnant; number of children; any abortions, miscarriages or children taken into care. Where they expected to have the baby (setting); had they discussed their BD in relation to pregnancy with any health professionals and some questions on current mental health and treatment, and previous mental health history. The women interviewed had all been given a diagnosis by a psychiatrist as recorded on their diagnostic and socio-demographic questionnaire. Their diagnosis of bipolar disorder was not in doubt as a) 16 of the 21 recruited had been referred directly by psychiatrists and the other 5, recruited through Bipolar UK, also gave detailed accounts of when and how they had received their diagnosis, also all from a psychiatrist.

#### **3.2.1.5 Sampling strategy**

A purposive sampling strategy was used in this study. This method was chosen for its ability to increase the likelihood that "variability common in any social phenomenon will be represented in the data" (Maykut et al., 1994). For the interview arm of the study, a purposive sample of psychiatric service users with BD was sought with respect to age (18-55), ethnicity and experience of pregnancy or consideration of pregnancy.

They were recruited via the South London and Maudsley NHS Foundation Trust and the charity Bipolar UK. Inclusion criteria were a diagnosis of BD and to be contemplating pregnancy or currently or recently pregnant. Participants were required to be euthymic at time of interview. Women without capacity to give informed consent, under the age of 18, and non-English speakers were excluded.

The following methods were used to identify participants:

- a) Recruitment was via referrals to the study from clinicians working in perinatal psychiatry clinics in the same catchment area, seeing women with BD who wanted to discuss pregnancy; were currently pregnant or had had children in the last few years. The latter group included women who had given birth up to 8 years previously as it was considered important to cover a breadth of experiences, though the majority had delivered less than 2 years previously.
- b) Care co-ordinators in generic community mental health teams mentioned the study to women and asked if women would like to participate; then passed their details on to me so I could telephone the woman, send her the invitation letter and participant information sheet and arrange a time to meet her.
- c) Advertisements in mental health centres with my contact details.
- d) Subsequently, the recruitment strategy was widened to include women identified through the national charity Bipolar UK (mostly women who had attended a workshop on BD and pregnancy where they had given consent to be contacted about research).

#### **3.2.1.6 Obtaining Consent**

Service users who were interested in participation were talked through the participant information and consent form (see Appendix 6). In line with the study consent procedures, all respondents were provided with a minimum of 24 hours to consider their decision to participate and were informed that they maintained the right to withdraw at any point during the study without giving any reason. All participants who

agreed to participate signed a consent form prior to commencement of the interview and retained a copy of the signed form in case they had further questions or changed their minds later.

#### **3.2.1.7 Setting and Design**

Individual semi-structured interviews were conducted with women between October 2012 and November 2013.

Interviews lasted between 25 minutes and an hour and were conducted face to face by myself in a location of the participant's choice: 16 were conducted at the home of the participant, four at the Institute of Psychiatry, Psychology and Neuroscience, Kings College London, and one at the offices of the charity Bipolar UK. All interviews were completed at a single appointment and were digitally recorded. Confidentiality was maintained (twice requiring a partner to leave the room whilst the interview was underway).

#### **3.2.1.8 Interview procedure**

Before each interview, I explained my personal interest in this topic and that interviewees may like to discuss support available for them as women with BD through the two charities I work for (on a voluntary basis), but I emphasized that this could be discussed after the research interview had concluded (at which time I also offered details of the charities if they were interested).

Following completion of the consent form and the socio-demographic and diagnostic questionnaire, an interview topic guide (as detailed above) was used to prompt and encourage participants to freely express their views. A shopping voucher (value £20) was given to participants to reimburse them for their time. Women taking part in the study were asked to talk about their feelings and concerns about becoming pregnant while coping with BD, and how they felt about being a mother with a mental illness. It was anticipated that it might be distressing for some women to consider these feelings and the risks to themselves and potentially their children. To minimize this burden as

far as possible, participants were monitored for signs of distress (I have experience of this situation myself, have conducted workshops with women on this subject and received additional training to deal with this). Strategies to reduce distress included asking the participant if she would like to take a short break, skipping questions that caused distress or offering to terminate the interview (this was offered twice but declined in both cases). If I was concerned about the severity of a woman's distress then I would have discussed this with my supervisor, a consultant psychiatrist, and decided whether any further action (such as contacting her key health worker) was necessary, though this was never needed.

#### **3.2.1.9 Safety Issues**

There are also a number of important issues to consider when conducting research with pregnant women in terms of safeguarding their unborn child. If a child protection issue arose, the concern would have been discussed immediately with my supervisor, Prof. Louise Howard (a perinatal psychiatrist) who would have advised me on any action needed and on sharing information with the clinical team. The consent form (Appendix 6) clearly states that all information is confidential unless it is considered necessary to disclose for example: when there is obvious or suspected harm to the child. I was also prepared for the possibility that participants might disclose other stressors when being interviewed so I also had information available about appropriate services e.g. if the participant had disclosed domestic violence.

#### **3.2.1.10 Issues of Confidentiality**

All information collected in interviews and socio-demographic forms remained confidential and in order to ensure the anonymity of participants during the transcription process, identifiable characteristics (e.g. names and addresses) were either omitted or replaced with pseudonyms.

#### **3.2.1.11 Methodological Issues arising from Interviews with Service Users**

Women who had recently given birth had their babies with them in the interview so it was sometimes challenging to maintain focus for me and for the mother if the child was demanding attention or crying. I tried to avoid this problem as much as possible by asking about the baby's sleeping time when booking appointments, but this did not always mean they would be asleep at the desired time.

Sometimes an interviewee's partner was present which affected confidentiality. As his presence may have inhibited the woman's ability to speak freely (for example, over whether he had exerted any pressure on her to make decisions in a certain way), I asked him to leave us alone as it had to be a private, confidential conversation (this proved necessary twice). Also, I found it challenging when interviewing pregnant women and new mothers as I did not want to raise issues which they might be avoiding thinking or talking about such as 'Will my child be adversely affected by my illness?' To avoid this possibility, I developed separate topic guides for pregnant women and new mothers which omitted this prompt (see Appendices 3 and 4).

#### **3.2.1.12 Data Management**

Each interview was audio-taped and transcribed verbatim. All quotes were anonymized and all data were stored securely on a university computer.

#### **3.2.1.13 Study Feedback**

The study consent form asked service users if they wanted to receive feedback about the results of the study. Shortly after the study was completed service users who had requested feedback were sent a report of the main findings.

#### **3.2.1.14 Reflexivity**

It is important to remain reflexive about one's own personal perspective when conducting qualitative research as the 'theoretical positioning' of the researcher's motives, presuppositions, and personal history can shape the qualitative inquiry

(Baillie, 2015, Jootun et al., 2009). It is essential therefore that researchers make explicit their perspectives and potential biases and adopt a reflexive approach, which considers how these beliefs/values influence the research (Yin, 2015, Stake, 2010). As a woman with BD who has had two pregnancies (one followed by hospitalization for postpartum psychosis), I was aware of the need to monitor my own biases and feelings (Carolan, 2003). I was transparent about my own personal interest in the subject from the start, stating my background in the project description to participants, and in the preamble to each interview. To avoid becoming involved in a conversation rather than a recording of each participant's views, I made it explicit from the outset that the interview would be wholly focused on her and that I would be happy to have a more general discussion of the issues and answer any questions after the interview had concluded.

In a research area such as this, where recruitment can be a challenge due to the relatively small number of possible participants and because of the sensitive nature of psychosis and young children, I felt it was an advantage that some women anticipated they would feel more comfortable talking to me as a fellow bipolar sufferer who had made the decision to have children, rather than a researcher without personal experience of the condition. I hoped that more women would volunteer to take part because they felt I would empathize with them (two women indicated this was the case). During the interview process, I felt my personal experience was an advantage because some women told me they were more at ease and inclined to be open about their experiences when talking to someone who could relate directly to what they were going through. I also found it useful, when women got upset, to be able to draw upon my experience working with the national bipolar charity Bipolar UK. I have run a number of workshops on this subject and have had to deal with women becoming understandably emotional when talking about these very private and often upsetting issues.

After completing each interview, I reflected in my personal notebook on the conduct and content of each interview and upon the effect, if any, it had had on me in terms of reviving memories of my own experience, particularly of psychosis or hospitalization. I



found this a useful monitoring exercise and a check against becoming progressively more emotionally involved with the subject. It was helpful that my own experience occurred over twenty years ago so I had had sufficient time to process it psychologically. I was also able to call upon the support and advice of my colleagues in the Women's Mental Health Section and my supervisor Louise Howard who is a psychiatrist.

### **3.2.2 Data collection via internet forum**

#### **3.2.2.1 Design**

The second arm of this study involved the posting of a thread on the e-community of the UK's national charity Bipolar UK (BipolarUK). Women with BD who are thinking about pregnancy are a difficult client group to access and so I decided to utilize the Bipolar UK e-community to augment the data I had gathered from the qualitative interviews to check if any other themes might emerge from this larger and more geographically diverse sample. As discussed above, this exercise was a means of enhancing the study's validity by triangulation. In recent years, there has been an increased use of the internet by individuals to share personal narratives, obtain support, and seek reassurance from others with similar experience (Anderson, 2008, Wesemann and Grunwald, 2008, Ziebland et al., 2004). The choice of using the internet as a data source is supported by Robinson (2001), who argues that internet narratives tend to be more detailed in contrast to verbal narratives, and the secure feeling of being anonymous allows individuals to share their innermost thoughts and feelings, thus producing richer data less encumbered by the influence of stigma.

#### **3.2.2.2 Ethical approval**

This arm of the study also received ethical approval from Camden & Islington Research Ethics Committee (11/LO/1469).

### 3.2.2.3 Setting

Bipolar UK is the only nationwide charity for people affected by bipolar disorder. It was founded in 1983 by service users and carers in London and currently has 125 peer support groups throughout the country. It was one of the first patient support organisations to set up an electronic forum accessed via the website ([www.bipolaruk.org](http://www.bipolaruk.org)) in 2005. The eCommunity is one of the largest web-based discussion forums in the UK, with 18,768 people currently registered and 622,345 posts made (20 August 2017). It is hosted and moderated by the charity providing a safe and secure environment for individuals to pose questions, assist others and openly discuss the challenges and impact of bipolar. The eCommunity is intended for people aged 18 and above. Members of the forum are required to register with their contact details (so that the moderators can contact them in an emergency) and use anonymous 'tags' or pseudonyms when posting online. Under the forum's Terms and Conditions, it is stated that postings referring to methods of suicide or promoting self-harm will be removed.

As a member (and trustee) of the charity, I had participated in e-forum debates before and seen several posts by women appealing for information about pregnancy issues so I anticipated that it might prove fruitful as a way of gathering more diverse opinions and insights into women's attitudes and their experiences of treatment. There are an increasing number of research studies which make use of the data available on the internet but most of them go on to e-forums and sample posts (Wesemann and Grunwald, 2008, Ziebland et al., 2004). For example Engqvist and colleagues (2011) collected 28 narratives written by women about their experience of postnatal illness by entering search terms such as *postpartum psychosis*, *puerperal psychosis*, *postnatal psychosis* and *narratives* and then examined them for their compatibility with the DSM-IV definition of postpartum psychosis. This gave them 10 narratives which they then analysed qualitatively. This approach has attracted criticism on ethical grounds (Rodham and Gavin, 2006). By contrast, I adopted what I consider to be a more ethically sound approach by describing the study initially, making it plain that I had ethical approval to conduct it and then inviting forum users to contribute, thus affording participants the opportunity to choose for themselves whether or not they

took part (as opposed to simply ‘using’ the data they had posted for the purpose of sharing with other forum users rather than for research).

#### **3.2.2.4 Procedure**

With the collaboration of the e-community’s moderators, I started a thread entitled ‘Bipolar and Pregnancy’ on July 11, 2014 which was closed on June 23, 2015. It asked about ‘the most important factors to consider when contemplating pregnancy’ for women with bipolar (see Figure 3-2 below), posing open questions based on the research project’s interview topic guide.

**Figure 3-2: Bipolar and Pregnancy post on Bipolar UK's e-forum**

From **moderator-richard** » Fri Jul 11, 2014 2:16 pm

Bipolar UK is working in partnership with a research project focusing on what women with bipolar think are the most important factors to consider when contemplating pregnancy.

For example

- To what extent are or were your thoughts on having children influenced by having bipolar?
- Do or did you have any concerns?
- Have you discussed this with your partner, family, friends and, if so, what was their attitude?
- Have you ever discussed this matter with any medical professionals? If so, how did that go? What was their attitude? Did you find it helpful?
- How much do you know about having a baby as a woman with bipolar? Do you feel you know what you need to know?

If we could produce a 'decision aid' of information and advice to help with this decision-making process, what do you think would be the best format: a leaflet, an interactive module on the website, an app for mobile phones - or something else?

Given the importance of this research (it is approved under Study Ethics code:11/LO/1469), we thought women on the eCommunity may wish to participate offering their views on these questions or any other related issues.

Whether you're a mum already, thinking about being one in the future or are the partner or relative of someone, please respond to this post.

Your posts/thoughts would be much appreciated and could be used within the project on an anonymous basis.

### **3.2.2.5 Issues of Confidentiality**

Anonymity was preserved and prior consent obtained from women taking part by clearly stating at the top of the thread 'Bipolar and Pregnancy' that the research was "approved under Study Ethics code: 11/LO/1469" and that posts "could be used within the project on an anonymous basis".

#### **3.2.2.6 Safety Issues**

There is always the possibility when posting about sensitive and potentially upsetting issues on an e-forum catering for people with serious mental illness that a post could provoke a response that might be dangerous (for example, a woman threatening to kill herself). Bipolar UK moderators are prepared for this possibility and experienced at handling it (the moderator can access the details of the individual and intervene). It states in the forum's Terms and Conditions: "Confidentiality. Where Bipolar UK has a concern that an individual's health and safety is at risk ...we will remove the posting and take appropriate action making a referral to or seeking advice from the police or another frontline service including for example, paramedics or social services". This is another way in which this particular method of internet research is preferable to alternatives.

#### **3.2.2.7 Study Feedback**

When the eCommunity thread was closed after 12 months, a statement was posted thanking all participants and assuring them that "the results of the project will be made available on the Bipolar UK website" (this was duly done).

#### **3.2.2.8 Analysis of data from interviews and e-forum**

Data were analysed thematically (Braun and Clarke, 2006) with the aid of the NVivo software programme. Transcripts were read several times and an initial coding frame developed. The appropriateness of the coding frame was checked through progressive iterations and reapplied to earlier transcripts as it developed (DiCicco-Bloom and Crabtree, 2006). Themes were determined by the data as well as a priori codes through axial coding. Themes from the e-forum data were combined with the interview data in the coding framework. The thread was kept open and posts were recorded until data saturation by this method was perceived to have been reached (Aronson, 1995). In order to address elements of subjectivity in the coding and interpretation of data, myself and another researcher (Hannah Savage, a non-service user researcher at the IOPPN, King's College) independently coded a proportion of the

interview transcripts before meeting to compare results and resolve differences. After achieving a 90% inter-rater agreement the results were then discussed with my supervisor (Prof. Howard) to achieve consensus.

### **3.3 Results**

#### **3.3.1 Sample characteristics**

##### **3.3.1.1 Interview subjects**

Twenty-one women were individually interviewed in person, with a mean age of 35.5 (21 - 49, SD 6.11). Sixteen were recruited from the South London and Maudsley NHS Foundation Trust (76%) and 5 from the charity Bipolar UK (24%). Different ethnic and socio-economic groups were represented: 10 White British women (48%); 3 white European (1 German, 1 Portuguese, 1 Irish) 14%; 5 black and mixed race (2 African and 3 Caribbean) 24%; 3 Asian (1 Pakistani, 1 Bangladeshi, 1 Sri Lankan) 14%. See Table 3-1 below for more details of participant characteristics. The ethnic diversity of participants reflected the overall composition of Greater London residents, as outlined in the 2011 census (Office of National Statistics, 2011).

***Table 3-1: Characteristics of 21 women with BD who were interviewed***

Characteristics	Frequency / percentage (N=21)	
<b>Age</b>		
20-30 years	3	14%
30-40 years	13	62%
>40 years	5	24%
<b>Ethnicity</b>		
White, British	10	48%
White, European	3	14%
Black or mixed race	5	24%
Asian	3	14%
<b>Employment status</b>		
Employed or doing voluntary work, FT or PT	12	57%
Students	2	10%
FT mothers	3	14%
Unemployed	4	19%
<b>Level of education</b>		
Graduate level or above	14	67%
A' Levels or NVQ qualifications	6	29%
GCSEs	1	4%
<b>Marital status</b>		
Married	10	48%
Co-habiting	1	4%
Single (including 1 divorced)	10	48%
<b>Pregnancy status</b>		
Considering first pregnancy	9	43%
Considering 2nd pregnancy	2	10%
Pregnant at interview	5	24%
Recently given birth	5	24%

Of the interviewees, 12 were employed or doing voluntary work, either full time or part time (57%); 3 were full-time mothers (14%); 2 were students (10%) and 4 were unemployed (19%). It was a well-educated sample: 14 had been educated to degree level or above (67%), of the other 7 women, 6 had A Levels or NVQ qualifications, and

one had GCSEs. Eleven women were married or cohabiting (52%), nine were single and one divorced. Of the 14 women who described themselves as having a partner, all partners were employed, 12 full-time, 2 part-time, and 10 of the men (71%) were educated to graduate level or above.

All women had been diagnosed with Bipolar 1. Some women had also been diagnosed with other conditions prior to the bipolar diagnosis including schizophrenia, depression or borderline personality disorder. The average age at diagnosis of BD was 25.8 (18-36). Nine women in this study were considering their first pregnancy (43%) and two were considering their second. Five women were pregnant at the time of interview (24%), for two of whom it was their first pregnancy. For those women who had had at least one child the average age of first childbirth was 30.7, while the 3 women who had had their first child when under 25 had not had a diagnosis of BD at the time. For women who already had a diagnosis of BD ( $n = 6$ ), the average age at which they had their first child was 34.6. Three women had had abortions (one had had four); 4 had had one or more miscarriages.

### **3.3.1.2 E-forum contributors**

Fifty more women participated via the Bipolar UK e-forum, contributing a total of 85 posts, though this data was given anonymously so no participant characteristics were available. This is a limitation of the study as it is not possible to be certain that all participants had been given a diagnosis of bipolar disorder by a medical professional. The majority referred in their posts to their conversations with their psychiatrists about pregnancy but it can only be said of all 50 that they self-identified as having bipolar. Some posts were framed as answers to the list of questions posed by the researcher, others gave accounts of their own experience and some responded directly to what others had posted to endorse, support or disagree with their statements. Figure 3.2 details the exact wording of the post which started the thread requesting forum members' input to "a research project focusing on what women with bipolar think are the most important factors to consider when contemplating pregnancy".



### 3.3.2 Themes

The thematic analysis of factors influencing decision-making around pregnancy for women with BD generated 5 superordinate themes: *Centrality of Motherhood*; *Contextual factors*; *Stigma*; *Fear* and *Experience of Services*.

Table 3.2 below illustrates the themes and sub-themes which will be described in detail with examples from the transcripts.

***Table 3-2: Views of women with BD: summary of themes and major sub-themes***

<b>Centrality of Motherhood</b>	<b>Contextual Factors</b>	<b>Stigma</b>	<b>Fear</b>	<b>Experience of Services</b>
Strength of desire to have children	Cultural and religious factors	Anticipated stigma	Fear of becoming ill	Accessing information
	Physical and psychological readiness	Social stigma against mothers with mental illness	Fear of medication harming the baby	Seeking help from professionals
	Biological clock	Cultural differences in social attitudes	Fear of being a bad parent	Experience of the birth and postpartum period
	Economic factors	Stigma from health professionals	Fear of passing BD to child	
	Family history	Stigma against women unable to breastfeed	Threat to relationship	
	Social pressure to be a 'Super Mum'		Fear of Social Services involvement	
	Degree of social support			

### 3.3.2.1 Centrality of Motherhood

A major theme running through all stages of the decision-making process was the strength of the desire to have a child - the 'centrality of motherhood'. Women referred to "having always wanted to have children" and many regarded it as part of the natural course of life, as this interviewee described:

*'One of the main factors that influences whether I have children or not is that ...I really believe that ...if I don't have children, I somehow haven't fulfilled my earthly purpose.'* P20

Many saw it as the next step after settling down with a partner:

*'It's a natural progression really, when you're married, you know, you want to reproduce.'* P13

This interviewee explained how important it was to her relationship and her family:

*'Everyone felt that having a child would be an amazing event and ...so everyone was very positive that a child would be an asset to our relationship and to the family'.*

Even the younger women in the sample who had been more recently diagnosed and were not yet considering long-term relationships were vociferous in their desire to one day have children, as this woman in her early twenties described the power of her maternal feelings:

*'I've always loved babies, and I have all these really, really strong maternal urges all the time'.* P20

The huge importance participant 18 attached to having children and her anxiety around it because of her illness made her acutely conscious of the need to prepare for motherhood:

*'I did feel a bit broody earlier this year. I felt like, 'I really want to have a baby, I really want to have a baby', but I know that ... mentally I'm not ready ...when you've got the responsibility of children, you need to be grounded and ...there's some more work that I need to do on myself first before I have children.'* P18

A woman on the e-community posted that, despite being “terrified of postpartum depression” and a long list of other worries, they were outweighed by her desire to have a child:

*‘I’m scared of all the statistics and the data - that worries me about becoming pregnant in the future. But ultimately my desire to be a mother is more than my worries. And I guess I will cross those bridges if and when they come’. [e-forum]*

Other women on the e-forum spoke of how their children were the most important thing in their lives and how they had a positive effect on their mental health:

*‘I definitely wouldn’t rule out having children if you are bipolar, as for me they are the ones that give me hope and a reason to continue’. [e-forum]*

### **3.3.2.2 Contextual factors**

Women’s attitudes were inevitably influenced by contextualizing factors from cultural and economic to physical and social considerations.

#### **3.3.2.2.1 Cultural and religious factors**

With this relatively diverse sample, there were a number of references to the significance of cultural and religious factors:

*‘In Asia they don’t believe in mental illnesses... many of my in-laws have witnessed me relapsing and they’re like ...Why is she like that? Why is she being strange?’ and ...I was upset about it.’ P5*

A woman of African descent described how her extended family were “harassing” her to have a child as they thought it would benefit her mental health:

*‘They keep telling me to have a kid ... my aunty ...was going on “you need to have a kid!” ...they were harassing me for a long time’ P14*

Religion also played a role in a person's attitude to having children. Having an abortion, for example, was not an option for some due to their religious beliefs, as this Irish-born woman who was raised a Catholic explained:

*'I have a thing about abortion, right? I know it's ...necessary in certain cases, but for me to fall pregnant due to my lifestyle and then decide I was having an abortion would have been a bit of a bitter pill to swallow'. P9*

A religious upbringing also played a role in this participant's decision to have a second child despite potentially life-threatening risk:

*'We're relatively traditional and... ...I'd always associated that in my mind with big groups of family' P12*

### **3.3.2.2 Physical and psychological readiness: '...got to get fit mentally and physically'**

Many women highlighted the need to prepare physically as well as mentally for the pregnancy and the birth, and pertinent to this factor is the fact that many bipolar medications cause weight gain:

*'I'm too fat at the moment to have a baby... I've got to lose 4 stone. I've been going to the gym a bit more.' P16*

An older woman who regretted not having had children, advised women with BD to think practically about whether they were mentally and physically fit enough and had adequate support for a child:

*'If you can't really look after yourself how are you going to look after a kid? ...you've got to think about your health, ...your nutrition ...You've got to look at your environment, where you're living...you've got to get fit'. P14*

### 3.3.2.2.3 Time pressure: 'The biological clock is ticking like crazy'

Because of the time involved in changing medications and preparing mentally and physically for motherhood, many women felt they needed to start planning well in advance:

*'This isn't the same as reading a pregnancy magazine or talking to your friends who are thinking of getting pregnant with no complications.'* P7

In addition, many women described the extra anxiety of feeling 'the biological clock' ticking, imposing a time limit on their decision making, and this caused more than one interviewee to become tearful at the interview. Many had delayed having children due to their illness, or sometimes due to the associated instability in their lives. As this woman posted on the e-forum:

*'Having bipolar has greatly affected my thoughts of having children. It's greatly delayed the decision and now I'm in a position due to age that I have to make the choice to have them or not have them ...[I] question whether it's the right thing to do or not'. [e-forum]*

*'We both felt that I was approaching my late thirties and that if we were going to have a child we should get on and try for one ...because the biological clock was ticking.'* P13

For some, they felt the extra dangers of being an 'older' mother complicated their decision still further:

*'I seem to spend my life in indecision... and there's only so long you can defer this decision... the biological clock is ticking like crazy and it turns out the biggest risk for me now is actually - as [the perinatal psychiatrist told me] - having a baby with Down's Syndrome because of my age.'* P6

Some felt the pressure from family to make a decision before it was 'too late':

*'[My mother would] say 'Oh you're getting older now, you must have a baby soon!'* P5

Even women who felt they 'had time' were worried that they were prevented from starting a family when their peers were doing so, in particular by health professionals:

*'When I was in hospital they said 'You can't have a baby for at least two years' and I remember feeling really, really upset about that in particular... now... happily, I am expecting a baby, but you feel very left behind because all of my close friends had had at least one baby by then.'* P3

Others acknowledged that they had probably run out of time:

*'I would really love [children]. At my age now, probably...the odds are ...stacked against me. There's still perhaps a window of opportunity... but I've probably come to the end of my childbearing years...' [P10, aged over 40, visibly upset].*

#### **3.3.2.2.4 Economic factors**

Bipolar disorder often has a very negative effect on sufferers' careers and economic independence, and one interviewee referred to her desire to be in a secure enough position financially to raise a child in the manner in which she herself had been raised, and so this had also delayed her trying to get pregnant:

*'[Because of] my illness, I haven't worked for years and ...I come from quite a secure background and whilst my parents didn't have a great deal of money, I had ballet and piano lessons and things like that and ...I wanted to re-create that...[but] due to my illness ...I have a great deal of doubt as to whether or not I could manage it.'*  
P10

Another woman, who viewed parenthood as "a massive responsibility", was also concerned at being able to provide for her child if she should become unwell and not be able work because:

*'...you worry a bit about the quality of life that you can give them if everything becomes ...unstable again.'*P15

### 3.3.2.2.5 Family history

For women who had had a parent with BD, issues of whether they could do a better job of parenting were particularly important, as this woman, who had agonized over whether to have a child for more than a decade, explained:

*'Obviously having a Mum who...was so unwell herself has had a big impact on how I feel about family life. I mean we had a very...disrupted childhood and not a happy family life. My big fear is that, without knowing it, I would end up reproducing that. ...So were I to bring a child into this world I would worry that I wouldn't be capable of being a great Mum.'* P6

This concern was echoed in a post on the e-community:

*'Having parents with mental health problems myself, there were times when I felt quite isolated and wished that I had someone who understood what I was going through as I didn't feel able to share it with my friends. This is one of the reasons why I want a second child, so as siblings they will always have each other and one child will not have to go through such difficult times alone.'* [e-forum]

### 3.3.2.2.6 Social pressure to be 'Super Mum'

Women described how the social pressure to be a 'perfect' mother exacerbated their feeling of being judged:

*'People judge mothers for every decision that they make ...about everything, you know ...from what you feed your child, ... whether you work or don't work ...even more so if you're bipolar.'* P12

Some spoke of feeling pressurized by the Western media-driven emphasis on being a 'Super-mum' or 'perfect mother', and worried that they couldn't live up to this ideal as women with a mental illness:

*'I know that if I did have a child I would want to be the best Mum, you know, I'd want to be Super Mum and ... I can imagine that I would exhaust myself and there's a lot of danger in that'.* P18



*'As a person, I have an element of wanting to prove myself to others ...so ...I still really want to prove myself as a good mother... kind of prove to yourself even more that you can do it with bipolar.'* P6

Aware of the potential negative effect of popular portrayals of motherhood in the media which ignored or denigrated new mothers with mental illness, one interviewee advised trying to block it out:

*'For any pregnant women but let alone pregnant women with bipolar just try and steer away from all the kind of mummy clap trap, you know the mumsnet rubbish and all of that stuff.'* P12

Many recognized the primacy of staying well - for their baby's sake as well as their own:

*'I think it's all very easy to believe the model of motherhood that we have, which is that you sacrifice yourself completely and you have to put ...your child's needs first ... but I think if you're bipolar ...the most important part of that is actually staying well ... It's not being selfish ... to prioritize your health.'* P12

### **3.3.2.2.7 Social support:**

#### **3.3.2.2.7.1 Importance of partner's attitude: 'He's my rock'**

In addition to the influence of family and social circles, most married or co-habiting women in this study referred to the importance of their partner's attitude as a factor in their decision-making:

*'I was like 'Let's have kids'. My husband wanted to have kids a long time ago, just after marriage, but I said we have to discuss [it] with the doctor because of my medications.'* [P4, contemplating pregnancy]

For many women, their partner's involvement in the decision-making process was critical:

*'I'm phenomenally lucky that I have my husband ...It's such a hard decision and [you need] someone who you can trust ...to think things through rationally.'* P12

One woman who had been ill with her first birth, said she had discussed having another child "endlessly" with her husband:

*'[He] doesn't say much but he wants to know what's going on ...and he does the research.'* P9

For another, who felt time was running out biologically, it was extremely hard to reach a decision:

*'Oh God, we've been considering the possibility of having children ever since ...a year after we got together. We've talked about it and talked about it and never reached any conclusion.'* P6

*'I just wanted to know ...that he wanted it too ...and also felt that it was worth taking the risk... it's ...the greater risk almost to him in a way [because he might lose his wife and have to look after their child alone], and so ...I needed to know that he had reached the same place, that's why I think we took a long time...' P12 (who left a gap of many years between her two children).*

Women were concerned about how much support they would need during the pregnancy and after the birth, but also over the need to provide stability and continuity for the child growing up in case they suffered further episodes of illness. For one woman the fact that she felt she could rely on her husband totally when ill had been an important factor in deciding to have another child:

*'He ...offered his support and said ... he would do his upmost to help deal with the child and then as it turned out he ...is an amazing Dad ...so he's been a huge source of strength and ...he is my rock in many, many ways.'* P13

Not all partners were as encouraging:

*'I was prepared to take the risk with my health, but my husband wasn't. We had a meeting with those involved in my care who were actually supportive. Looking back I was too unstable, not to have a*

*child, but to give one a stable life. How would my husband hold down a job looking after a child when I was having a period of illness?’ [e-forum]*

As a woman with bipolar, the idea of having a baby without a partner was impossible for some:

*‘Having the right person to have the baby with has always been the most important thing for me and knowing [my husband] and how stable our relationship is, that’s really important to me... I wouldn’t have ever considered [being a single mother ...especially with bipolar. I just think it would have been a big mistake...I think if I hadn’t been lucky enough to meet [my husband], children just would have been off the cards for me.’ P15*

For men who had not witnessed their partners suffer from a bipolar episode, it was hard to know what to expect:

*‘He said he wouldn’t know how he would react, whether he will be able to cope... they explained the condition to him ...we had lots of open talks about it... and he’s watching out for any signs in me changing behaviour... He was very strong ...throughout that my health is more important than the baby’s health.’ P4*

Not all men in this sample were in unison with their partners over how the decisions should be approached. Some were very against their partner taking medications during pregnancy:

*‘I know [my husband] is dead against me taking any medication, probably even herbal remedies or anything...he’s really nervous ...of what it might do to the baby. And I’m in agreement with him but not as wholeheartedly like, if I’m putting myself at risk ... I would be prepared to take medication during pregnancy if...if I was unwell enough to be hospitalized I suppose is what I mean.’ P5*

### **3.3.2.2.7.2 Social support: importance of family: ‘My Mum has been amazing’**

Another factor in decision-making was awareness of the amount of support they might need postnatally, both to avoid an episode of illness or to be able to cope if one occurred.

*'You've got to think is your family supportive? Do you have a support network around you?' P14*

Many said how important support from their family was, those with partners as well as those bringing up a child alone.

*'My Mum has been amazing and in fact three days after I'd had [the baby], she turned up at our house ...essentially because I'd been advised not to wake up for night feeds ...because **there** was a fear that I might kind of tip over into illness. So she actually did the night feeds and stayed on a camp bed in the front room ...She's been a huge source of support.'* P13

The important role this support could play in preventing an episode was recognised, particularly in relation to allowing the new mother regular sleep:

*'[My husband] and I have discussed what would happen if I did become unwell, and ...we were thinking perhaps his Mum or my Mum ...would be available. They're both retired and would support us if...an emergency situation happened.'* P15

A woman whose husband doubted how she would cope with a baby, was confident that she could rely on her family to help:

*'I was telling my husband, if it gets too much where I need to sleep then I will just send baby to my Auntie, the one from Bangladesh. I'll drop the baby there for just one day and I'll catch up with my sleep'.  
P5*

Most single mothers in this study said they relied on their mothers for support, or in this case, a good friend:

*'[For the last birth] I had my Mum here ...[so] I had my sleep. She's not coming [to England] this time because I have a good friend here and she's coming to cook, to iron...she's my best friend ...she's a good support.'* P8

Those without such support recognized that they relied on services more heavily:

*'I don't have any family around me. I have some friends. And therefore, having the support of the perinatal [team] ...was very crucial to me in ways I didn't really understand until afterwards'. P9*

### **3.3.2.3 Stigma: 'It's almost like: 'We shouldn't really let the mad people have children'**

As one of the three overarching themes which pervaded all stages of the decision-making process, women's consciousness of stigmatizing attitudes towards them as people with a mental illness was evident, and they feared it was assumed they weren't capable of being good mothers. Reports of different types of stigma were numerous and sub-themes were: a) anticipated stigma b) experienced stigma, including from family/friends, health professionals, and the media, and c) stigma against women unable to breastfeed.

#### **3.3.2.3.1 Anticipated stigma: 'What if you drown your baby?'**

Anticipated stigma is the term used to describe a person's own awareness of stigmatizing attitudes towards her - attitudes which may upset and depress her, erode her self-confidence and in some cases deter her from seeking help when she needs it. For example, this study's youngest participant said that she had always very much wanted children but she was alarmed at the idea that her illness could potentially make things difficult. She expressed how reluctant she was to disclose her BD to people, and how much more difficult she felt it would be to conceal her illness once pregnant:

*'Because, you know, a lot of people might not know you have bipolar until you're pregnant and it has to be much more public ...so, yes, I worry whether some of my friends who I think are really supportive will then turn around ... and say ... 'Should you really be having children? ...You've got mental health problems! What happens if you, kind of, drown your baby?' You know, something awful like that.'* P20

This concern was echoed by another young interviewee in her 20s:

*'My worst fear is people thinking I'm less capable because I've got bipolar ... I don't want people to think ... 'she won't be able to look after her kids' ...that's a horrible feeling.'* P21

Negative social attitudes towards mental illness made them reluctant to talk about their desire to have children and led some women to conceal the implications of their illness for their pregnancy from all but their most trusted confidantes:

*'...I haven't told anyone, ...my very closest friend ...was the only person I told, because I feel that other people ...feel it's a stupid thing to do ...and ...they'll be judgmental.'* P12

### **3.3.2.3.2 Stigma experienced against women with mental illness having children:**

#### **'It's never going to work out well'**

Rather than feeling supported, ignorance and stigma about bipolar alienated several women from family and friends, as this young woman said:

*'...I try not to tell everybody, you know? ...It's hard to tell older members of my family that I've got mental illness ... they don't get it, really.'* P20

Women described feeling awkward and somewhat alienated in generic support groups such as antenatal classes. Because of the stigma against mental illness, they didn't feel able to reveal their experience, and many felt 'normal' mothers-to-be wouldn't understand the unusual challenges they faced:

*'[This pregnancy] I just stayed away from NCT [National Childbirth Trust] if I'm honest ...And the 'sisterhood' is something I could do without as well I've decided ...my experiences are too rarefied for that type of open forum really.'* P9

Some felt the stigma they experienced in society was partly driven by the "very negative" presentation of mental illness in the media, particularly in relation to pregnancy and motherhood. This expectant woman described a respected pregnancy advice book she had bought, which contained "one little column" on mental health, "and it's one of the most depressing things I've ever read":

*'Basically it says ...due to ...the social problems that people with mental health problems have, it's a very bad start for the baby and ... it's almost like, 'We shouldn't really let the mad people have children because it's never going to work out well' and, and I just thought Gosh really?' P3*

Sensationalist news stories focusing on the very rare instances of psychotic mothers harming their children had alarmed and depressed some:

*'It's just the scare stories isn't it? It's the very occasional person with severe postnatal depression who harms her child that's in the media ...not the people who've managed ...it's really sad. It frustrates me the way bipolar is depicted.' P3*

#### **3.3.2.3.2.1 Cultural differences in social attitudes to mental illness**

Some women from immigrant communities alluded to the different way their family and friends regarded mental illness, for example, a German-born woman thought that greater stigma existed in the UK than in her native country:

*'It's like a vicious circle because someone not talking openly about it reinforces the stigma in a way. In Germany everyone knows about it, my family, my friends and we speak about it openly ... I'm not telling mums here, which is sometimes a bit strange because I'm normally very open about it, and if you can't say the truth in a way it's a shame. But then the English are much more reserved and don't say everything directly so I think it's just the English.' P4*

A woman in her twenties who had lost her mother, said it was more difficult to rely on her West Indian grandmother for support: *"My grandma ...doesn't think I should have children because of my bipolar"* (P18). And an Asian woman said that most of her family didn't recognize that her condition could be treated:

*'In Asia they don't believe in mental illnesses. They think that you're just mad and that's it.' P5*

#### **3.3.2.3.3 Stigma from health professionals**

Some women reported discriminating attitudes directly from health professionals too. A woman posted on the e-community that her efforts to get fertility treatment had

brought “the medical profession's internal stigma towards Mental Illness right to the fore.” Convinced that her GP and gynaecologist had “acted together to jeopardise my access to treatment”, she had successfully brought a case against them for unfair discrimination:

*‘The IVF was unsuccessful in the end ...and I am facing a different type of stigma in a private clinic.... Been declined egg donor treatment, due to diagnosis of BD!’ [e-forum]*

Many women reported that they felt stigmatized by the health professionals they encountered:

*‘I do think that amongst some members of staff in the Trust ...it’s implicit that they view those of us that have got bipolar as maybe not [pause]... that [we] wouldn’t have adequate parenting skills.’*  
P10

Another woman spoke of the stigmatizing attitude on the maternity wards:

*‘In hospital ... even with the midwives - I still felt there was this kind of thing ... because I have bipolar. ... The perception they make me feel that they have of someone who has bipolar - that you’re kind of different to everyone else.’* P17

This participant had had considerable contact with mental health services in the past, including during three previous pregnancies, but had only recently had her diagnosis changed from depression to bipolar disorder, and said she was very aware of being treated differently as a result:

*‘I feel very watched ...whereas before I would talk so openly to professionals about what I was going through ... I feel almost like I’m watching what I’m saying to professionals now that I’ve been diagnosed. Because, to them, bipolar is this high red alert ... so I am a bit cagey sometimes about it.’*

Non-medical staff also displayed stigmatizing attitudes, as this woman posted on the e-forum about the involvement of the Child Protection Services when she became ill during her pregnancy:



*'They made life even worse and made me feel like bipolar meant that you automatically would never be good enough to be a parent.'* [e-forum]

#### **3.3.2.3.4 Stigma against women unable to breastfeed: 'I spent the first year ...in a hair shirt':**

Women described how upset they were by the stigma directed against them when they couldn't breastfeed their babies due to their illness. As one woman said: "the biggest issue is how do we explain we're not breastfeeding?" (P4)

A woman who believed her attempt to breastfeed her first child had contributed to her having a postpartum psychosis, very much regretted that she couldn't breastfeed her second child:

*'I was really quite upset about that ...even though ...I'm really unhappy that I can't breastfeed, it's not worth taking any risk at all. I know that people do get a bit obsessed with it. And I think yes it's a good thing but come on...what's more important: that you get better and that you don't, you know, poison your baby with strange drugs?' P2*

Some women felt the fact that they weren't breastfeeding meant they were perceived by maternity staff and other new mothers as inadequate, as one said: "I've been just wanting to be treated as a normal expectant mother" (P3) but attending antenatal classes had made her feel she would be failing as a mother if she didn't breastfeed and made her feel guilty and unhappy. Participant 4 agreed:

*'The only thing that I've found extremely negative throughout was the emphasis on breast feeding, which I completely support and I would have loved to breastfeed, but ...everywhere, even in hospital ...it was always people looking and it was 'Why don't you breastfeed?' and ...also the whole postnatal walls are plastered with breastfeeding and ...it was really difficult.'*

This view was echoed by many women who said they found the postnatal ward a very uncomfortable place as a result:

*'I detested staying [on the postnatal ward] ...I really did. Particularly because being on lithium, I was bottle-feeding and therefore I was a child of a lesser god and so was my child. ...I got a lot of 'Why aren't you breastfeeding?' 'Why? Why aren't you breastfeeding?' 'Why aren't you breastfeeding?' and it was like, 'Uh, do you want to read my fucking notes please? And do you want to not talk to me like that? ...Three days [I was there] and I never heard any of them talk to anyone else like that.'* P9

One woman thought stigma against bottle-feeding had increased in recent years:

*'I think tides shift so [now it's gone back] to breast is best which very much dominates, so there's the NCT ... the breastfeeding lobby and there's the whole judgmental thing you know, 'Oh you're going to damage your baby if you don't [breastfeed].'* P12

A further practical consequence of the perceived antipathy to anyone not able to breastfeed was that women didn't receive the help they needed:

*'...nobody showed us how to feed her [with a bottle]. And we hadn't a clue. And finally I sort of ... basically begged someone to, but I found that the level of interest shown by the majority of the nurses in there was very scant - it was kind of shocking.'* P9

#### **3.3.2.4 Fear: 'I was quite terrified'**

Because of the risk of having a serious episode during or especially after pregnancy - particularly if they had stopped or changed medications due to the risk to the foetus - many women were very frightened at the prospect of being pregnant. This fear was not only focused on the health risks to mother and baby; a number of other concerns also caused anxiety, explored in this section under the following sub-headings: 1) fear of becoming ill; 2) fear of damaging the baby; 3) fear about their ability to parent with bipolar disorder; 4) fear that their child would inherit BD; 5) fear that a severe episode posed a threat to their relationship, and 6) fear of Social Services' involvement.

#### 3.3.2.4.1 Fear of becoming ill

A young woman who described herself as “constantly thinking about having kids”, was nevertheless “terrified” to think about the implications of her BD diagnosis:

*‘I definitely do want to have kids. It’s something I’ve always wanted ...but ...it’s too scary to think about to be honest... P21*

Similarly, it was the strength of her desire to be a mother that compelled a twenty-year-old interviewee to find out about the risks associated with pregnancy for women with bipolar. She said the professionals hadn’t told her anything about it (despite being put on Lithium) except that she should use contraception, so she attended a charity-run workshop on the subject and was shocked by what she learned:

*‘It was scary [learning about the risk of Postpartum Psychosis] ...I was quite terrified. I thought, ‘Oh my goodness ...that sounds really awful’. P20*

But she said it still wouldn’t deter her from having a child if she met the right partner. Others were scared of stopping or changing medication which they thought they would have to do:

*‘I’m very fearful about reducing or coming off my Carbamazepine, that’s something that ...I would want to do in the first trimester. I’m fearful at the possibility that I’d suffer with postpartum psychosis. [pause] ... God actually I can barely even think about that.’ P6*

This fear of having to stop medication while pregnant had prevented Participant 7 from starting a family for several years:

*‘I’ve always wanted children and the only thing that’s ever stood in the way was the thought of the lithium because obviously it’s more dangerous.’*

Some women on the e-community explained how fear had been the major factor in deciding not to have children:

*‘I would be terrified of having postnatal depression and doubt my ability to take care of myself and a child.’ [e-forum]*

Others posted that fear had prevented them from getting pregnant a second time:

*'I would love to have more but I am trying to weigh up the pros and cons because I am scared of what might happen.'* [eforum]

Some interviewees who had had one child had also decided against having a second because they “couldn’t face the prospect of getting ill again” (P2) and being separated from the first child while in hospital:

*'It was just too difficult for everyone ...it's a fairly dead cert that I would become ill again and ...how would the family cope ...who would deal with the childcare for the existing child? ...it was just too much of a damaging experience.'* P3

#### **3.3.2.4.1.1 Adoption, fostering and surrogacy**

Because of the high risk of a recurrence of illness, a number of women said they had even considered adoption or surrogacy:

*'I looked into surrogacy a bit, and I looked into adoption but my husband ...didn't want any of that.'* P7

These ways of becoming a parent were viewed as providing an alternative to the risks of giving birth, but most felt that they were unlikely to be ‘allowed’ to adopt because of their medical history, even if they had been well for many years. Some said they had asked medical professionals about this but could not get any information, for example, when one psychiatrist was asked if adoption was a possibility, “he said it wasn’t his area and he couldn’t say” (P4).

Another woman, who had deliberately refused to be hospitalized when very ill because she didn’t want it to jeopardise her chances of becoming a mother, said she had looked into the possibility of fostering or adopting a child:

*'Being realistic, you know, I don't think I'd be allowed to adopt even though I've never been sectioned. There are enough hurdles to jump for anyone normal when it comes to adoption and ...working on the premise that I got knocked back, how would I deal with that?'* P10

#### **3.3.2.4.2 Fear of medication causing harm to the baby: 'It's so risky'**

Because of the possible teratogenic risk to the foetus of taking medication and the poor research in this area, many women in this study were extremely fearful that they might harm their baby by remaining on their medication:

*'I'm scared that anything I take might affect a future child that I have. I don't want there to be problems like any birth defects or anything like that - that scares me.'* P21

Weighing this risk against the possibility of getting ill when medication-free (and so risking having to take even more medication or even being forced to consider abortion) was described as extremely difficult and made some women very anxious, as participant 16 expressed:

*'Because I take medication and I'm thinking that might affect the baby, harm it in some way, so sometimes I think I'm better off not having a baby'.*

#### **3.3.2.4.3 Fear of being a bad mother: 'Being a mum with bipolar...it feels huge':**

Concern over their parenting ability was a significant worry for some, particularly as mood episodes can be triggered by lack of sleep and extra stress. For example, Participant 16 was preoccupied with:

*'whether I can step up and be a proper parent really, it's a lot to consider ...It's 24 hours with a baby ...I don't want to become a bad parent'. P16*

Worries about sleep deprivation - a major trigger for bipolar disorder - was a recurrent theme:

*'The stuff that I struggle with is ...can I cope with the sleepless nights for a year? you know? 'How would we work it out practically?'* P6

Other women also worried about being able to cope:

*'I have...concerns around the medication but I think more importantly sort of self-doubt as to how I would manage a*

*pregnancy and then how I would manage caring for the child’.*  
P10

Some recognized that most mothers without BD worry about similar things:

*‘I was concerned about how I might deal with ...the pressures of being a mum and ...suddenly having a small person on the scene who is very vulnerable and whose every need needs to be catered for. I think a lot of my fears and concerns overlap with those of so called ‘normal’ parents.’* P13

One woman voiced the fear of being so ill she might harm her baby:

*‘There’s so much negative potentially that it puts me off...I’m a bit scared ...realistically if I harmed my baby that would be the worst ...‘cos I might get psychotic and do something really daft...’* P16

Many thought that, on a day-to day-basis, mood swings weren’t very compatible with good parenting:

*‘The thing I worry about is ... being consistent ... as a mother. I worry about overreacting, I worry about being withdrawn ...and maybe by worrying about them and giving them my consideration I am probably less uneven...than I would otherwise be.’* P9

A woman on the e-community described her struggle to be a good parent - so much so that it deterred her from having another child:

*‘I wouldn’t have another baby. My experience with my daughter has been a long hard road, bonding with her only happened when she was around 1½/2. And I feel a bad mum with all my ‘issues’ like when I snap and scream, I worry she will grow up confused about why one week I’m very enthusiastic and loving and the house is amazingly clean then a few weeks later I’m laying on the sofa screaming, shouting and the house a complete tip. I wouldn’t cope with another baby, my child is enough to keep me on my toes, and keep me going.’* [e-forum]

A woman responded on the forum by describing how she had gradually overcome her feelings of guilt:

*'I spent a lot of time worrying that my daughter would turn out like me and that I am a bad mother due to mood issues. I have made the decision not to have another child...[but] I couldn't be without my wonderful daughter. I now accept that I'm a good mother who happens to have bipolar and I explain things to my 4-year-old in ways I hope she understands.'* [e-forum]

Several expressed a fear of being a burden to a child:

*'I also am worried of bringing life into the world, that may at some point have to act as my carer - children that I would be in charge of caring for their every worry, may have to worry about me, and care for me. That scares me.'* [e-forum]

But not all women felt their illness would inevitably make them a bad mother:

*'When I'm well, I am very well and function well and effectively and ...there's no reason ...why I shouldn't be an adequate, normal mother.'* P13

Furthermore, a woman in her late forties, who still yearned to be a mother, thought motherhood had a positive effect on women with mental health issues:

*'I feel people with bipolar ...should be allowed to have children ...[Before] ...they took away their children, or they advised them not to have children. But I noticed from my friends who did have children, it kind of stabilised them when they started looking after their kids.'* P14

#### **3.3.2.4.4 Fear of passing on bipolar disorder: 'a sobering possibility'**

A number of women expressed concern about passing on their illness to their offspring, particularly if they had several relatives with the disorder:

*'My dad's bipolar as well...and ...there's quite a pronounced streak in the family...My dad... said he feels guilty that he passed on the illness to me [even though] at that time ...I don't think they knew about the fact that the illness could be transmitted between generations'.* P13

For this woman, the genetic issue was the first thing she mentioned when asked about factors influencing the decision to have a child or not:

*'I am concerned [my daughter] ...might display signs of the condition... and it's the last thing in the world that I would wish upon her ...so that was a ...sort of sobering possibility. It wasn't enough to deter us from wanting to have a child but it was something that we did ... discuss quite frequently...and were concerned about.'* P13

However, like other couples in this study, this woman and her husband decided they were well placed to help if their child did develop the condition and this was echoed by a woman posting on the e-forum who had had her children before being diagnosed:

*'I hope [my daughter] never develops BP but if she does I will be there every single step of the way holding her hand tightly.'* [e-forum]

Many women on the forum expressed fears about passing on their illness, and so had decided not to have children:

*'Like others I am scared of the rather high statistic I believe it's 15% more likely to get Bipolar if a parent has it. That scares me that I may be bringing life into the world that may suffer so strongly. Something I wouldn't wish on anyone let alone my own flesh and blood.'* [e-forum]

*'I would never forgive myself for bringing a baby into this world and put it through a) the unpredictability of my functioning and b) the possibility of the baby having this illness'.* [e-forum]

#### **3.3.2.4.5 Threat to relationships: 'It could split us up'**

One woman explained that although she and her husband both had good jobs and were comfortably off, she was worried about the emotional pressures a baby would bring because of her bipolar disorder:

*'you've got these incredibly intense pressures on relationships that the illness brings'.* P7



Others concurred: 'Having a baby...might be putting too much pressure on [my partner] - it could split us up.' P16

A woman on the e-community agreed that this was an important consideration:

*'I have made the decision not to have another child because I don't think my body would cope with doing it all again and I do not want to jeopardise the relationships I have with my daughter and husband'. [e-forum]*

For some, their partners were not as enthusiastic as them about having children, whether because of the risks involved or just generally. Asked if her partner was keen to have children, Participant 6 said:

*'Actually no, he's not. And this is now our big discussion because I feel like I desperately ... suddenly ...feel like I really want to try. But I don't want to do anything that will jeopardise our relationship...so it's a difficult one'.*

The decision to stay on lithium while pregnant and risk harming the baby was felt acutely by Participant 4, who was concerned it would affect her relationship with her husband:

*'So I ...was worried that the baby would have a heart defect and would either die or would really struggle throughout life ...and I was scared that... I would take on the blame ...[and] my marriage would really suffer because of that.'*

#### **3.3.2.4.6 Fear of Social Services: 'The stress that it can cause is disproportionate'**

A number of women were fearful that Social Services might be called in because of their mental health issues, and whether that could mean their child being taken away from them. As this contributor wrote on the e-forum, having a diagnosis of bipolar heightened the risk of Social Services removing the baby:

*'I'm scared of getting pregnant again because I don't want my child to be taken away. I am capable of looking after my son but if I get pregnant again now that I've been diagnosed, I don't know if I will be deemed fit to look after a newborn. It scares me so much. I want another baby so badly but might have to accept that I never will.'*

Women revealed that this fear had prevented them from asking for help:

*'[After the birth] I felt I was in an altered state of reality and I could hear sounds in my head. I was terrified of seeking help, as I thought if I revealed how I felt she would have been taken into care.'* [e-forum]

One worried it might be too much to cope with emotionally if it were to happen:

*'I know what it's like to be in a psychiatric unit but I don't know what it's like to be in a psychiatric unit and have the possibility of having your child removed from you, or the trauma that that would involve...I actually try not to think about that.'* P6

Another said:

*'I spoke to my Social Worker, she said ...Social Services probably will be involved ...to hear that did scare me.'* P1

That comment came from a single woman with a long history of mental illness and involvement with services, but even women in stable relationships with plenty of family support feared Social Services' involvement. For example, this was the number one worry for one mother looking forward to having a second child after her first son hadn't been allowed home because he wasn't gaining weight:

*'They decided without ever having met me or spoken to me that there was a suspicion of neglect... it was just horrible ...so [this time] I was just really concerned about Social Services'.* P2

Because of their diagnosis, several women were told when pregnant that Social Services were likely to be visiting them after the birth and for most this caused them stress and anxiety.

*'The stress of the idea of someone coming into your home to assess you is just [rolls her eyes] ...especially because they [Social workers] don't have a great rep. They're sort of like the Child Catcher General - that kind of reputation, you know? ... the stress that it can cause is totally disproportionate to what they're trying to achieve.'* P9

However, one woman pointed out the positive consequences of Social Services' involvement, recognizing that they could provide extra support which she valued:

*'It's risky having a baby ...I'd have to be a really good parent ...if the social were involved that's cool, 'cos if there wasn't a risk I wouldn't have parenting classes or social services [provided for me] ...I'm glad ...because I'm not going to be on my own, I'll have a little bit of support, so that's good in a way'. P16*

### **3.3.2.5 Experience of Services**

There was diversity in experiences of services, sometimes due to choice (one interviewee did not want to be treated in a Mother and Baby Unit (MBU) as she feared the severity of her illness postnatally would require separation from the baby), but more often due to the disparity in the level of local service provision. Some areas of the country have well-developed specialist perinatal mental health services, others do not, and preconception counselling and MBUs are not equally accessible to all women. Some women had been referred to a specialist perinatal service for preconception counselling, others were not. The former reported a high level of satisfaction, and several women recounted how they had only finally got the information they needed when they had actively sought advice from such a specialist. On the whole, women felt that general psychiatrists – and definitely GPs – lacked training and knowledge in this area so those who were not referred to a specialist felt let down. Women talked a lot about their experience of services and how local provision, or lack of it, was often a factor in how confident they felt about going ahead. Many said it had relieved their anxiety to be given a tour of the local MBU, for example, or reassured that they would have a private room on the ward (to help with sleep). Those who were already mothers were much more concerned with decisions around the birth and postpartum: expressing a desire to try to avoid stress and sleep deprivation by requesting induction or an elective C-section.

The major sub-themes in this section are: *Accessing information; Seeking help from professionals and Decisions around the birth and postpartum.*

### **3.3.2.5.1 Accessing information: ‘If you know what questions to ask, you’ll get information’**

Many women in this study felt disempowered and poorly equipped to ‘weigh the risks’ of having a child as it was difficult to find reliable information on the subject. As one said:

*‘What’s lacking is a) information about medication and conception, and b) the support that is out there for a service user ...if one were to get pregnant, what then kicks into place?’ P9*

A 42-year-old who said she had been trying to get advice on pregnancy for ten years, said that health professionals had not talked to her about the possibility of Postpartum Psychosis:

*‘[I received] very little information about postpartum psychosis. Most of the information that I’ve gleaned about that, I’ve gleaned from Bipolar UK...There needs to be far more concrete information given to women such as myself ...because ...it’s all well and good psychologists and care co-ordinators saying that this service is out there if the psychiatrist isn’t fully co-operative.’ P10*

This was echoed by a post on the Bipolar UK e-forum:

*‘I have not found anything useful or supportive from [discussions with health professionals] as nobody has seemed to be "qualified" to discuss this with.’ [e-forum]*

It was pointed out that mental health issues were generally ignored in books about having a baby:

*‘They have the kind of physical ‘what to take or what not to take when you’re pregnant’, but I think it would be lovely if there was a mental health equivalent that was written in a way that wasn’t sort of... finger wagging’. P2*

Many reported searching for information themselves on the internet unsatisfactory and anxiety-provoking:

*'I actually find - searching for things on the internet - you come across all sorts of unhelpful things because random people... decide to post something and ...you think 'Oh my goodness, am I going to end up like this person?' P3*

Others concurred that they had used the internet to do research for themselves:

*'I was kind of scrabbling around you know, trying to do research myself and I did a bit online ... There are studies out there which you can access if you 'google' them'. P13*

Conversely, one contributor to the e-community highlighted the possibility that emphasising the need for detailed information on the risks and dangers of pregnancy for women with BD and what needed to be done to avoid them, might have a detrimental effect:

*'I am concerned that if the entire focus is on what goes wrong and what can we have in place to limit and manage that risk, then this will increase the perception of bipolar mothers as dangerous pregnancies and increase stigma from health professionals.' [e-forum]*

A woman posting on the Bipolar UK e-community called for Third Sector organisations to be involved in dissemination of this information:

*'The NHS needs to prepare mothers for all eventualities during and after birth and work with the likes of Bipolar UK to ensure mothers ...have the right information. It would be invaluable.' [e-forum]*

#### **3.3.2.5.1.1 Timing of information: 'It should have been mentioned to me'**

Many women also pointed out that it would have been useful to receive more detailed information much earlier, soon after they were diagnosed. Several felt they should have been told about the possible implications of pregnancy long before they were at the point of considering having children, despite the danger of being frightened by the information:

*'They never really went into detail ...about the fact that I might ...want to start having children ... Now that I know about things like postpartum psychosis and not being able to breastfeed on certain*

*medications, ...I think that's definitely something ...that should have been mentioned to me' P20*

The need for advance preparation was echoed on the e-community:

*'When I decided to start a family I had to come off a dangerous medication for unborn babies called sodium valproate. This took time to titrate and change to a safer drug called quetiapine. I do feel it would have been more beneficial if women of child-bearing age were initially started on a drug that's safer in pregnancy so that if an accident were to happen or someone did want to start a family there would be less risk.' [e-forum]*

A woman posted on the e-community that antenatal classes would be an ideal place to raise awareness of potential mental health issues around pregnancy and birth:

*'I was concerned [about] postnatal depression as I'd suffered depression before. The nurse leading the NHS antenatal class dismissed my concern with the comment 'it's just like baby blues but a bit worse'. Antenatal classes are the best place to give literature to prospective mothers about the risk of mental health problems occurring after birth - the class I went to covered none.' [e-forum]*

### **3.3.2.5.2 The 'High Risk' label: 'a double-edged sword'**

Some women reported that their fear of getting ill when pregnant or postnatally was greatly exacerbated by being told their pregnancy was officially labelled 'High Risk' - a categorisation used to flag up women that might need extra monitoring. As this European mother with BD said of her second pregnancy:

*'I don't think it's a good idea when the doctors give you too much pressure. Because you will think you are sick when you are not sick ... you feel more scared ...Okay, say you have a risk, don't say 'very high'. Because sometimes the words are too strong ...and that's what happened to me ...I feel like 'Oh my God! They're **sure** I'm gonna get sick' ...it was the time I started [to get] worried. Not before ...I think this is not good, because you feel more 'Oh!' you're going to die, you know?' P8*

For Participant 13, the 'High Risk' label had advantages as well as disadvantages:

*'I was deemed to be 'high risk ...which made me feel partly special you know because I was worthy of extra attention but at the same time a bit nervous because it suggested that things might not go smoothly and that there was a danger involved in the pregnancy. So it was a sort of double-edged sword really.'*

### **3.3.2.5.3 Need for research**

In addition to a general improvement in the accessibility and quality of information on BD and pregnancy, many women called for more research to be done in this area:

*'I think more research needs to go into bipolar drugs and pregnancy so bipolar mums can feel safer on their drugs'. [e-forum]*

Another poster on the e-forum called for more research on child outcomes:

*'What I need to know about is the effects and outcomes of medications - and research is lacking, I know ethics limits research in this area but there needs to be more research. Reading about the odd case that had a good pregnancy outcome on x,y,z medication is only helpful to a certain extent, what happens to these babies as they grow up and into adults?' [e-forum]*

One young mother-to-be asked for researchers to focus more on why some women with bipolar don't get ill during pregnancy and postnatally, with a view to that information being useful to others:

*'...it is understandable that the immediate focus would be on how to prevent things going wrong. But I think that needs to be balanced by research into a broader perspective on what goes right as well ... the current focus seems to be very much framed by the concept of reducing risks rather than **maximising positives**. I suspect there are women with bipolar who thrive during pregnancy and postpartum even without having special maternity care etc. and I think it would be useful to also look at why things work for those ladies, in addition to the current focus on what can be done to prevent things going wrong.' [e-forum]*

#### **3.3.2.5.4 Seeking help from professionals: ‘a bit hit and miss’**

When seeking advice about pregnancy, most women with BD saw their GP or general psychiatrist (though one woman turned to her social worker for advice in the first instance). The response they received varied widely: some were immediately referred to a specialist perinatal service for preconception counselling, others were not. As one woman said, “most people are going to be reliant on the psychiatrist for advice but then that’s a bit hit and miss: it depends on your psychiatrist and your relationship with them” (P13). Hence I have divided this section into those who had problems getting help from services (acknowledging the overlap with section 3.3.2.3.3 on Stigma from health professionals) and those who had a much better experience.

##### **3.3.2.5.4.1 ‘Bashing my head against a brick wall’: Problems seeking help from professionals**

Many women reported difficulties getting information from health professionals about the relative risks posed by pregnancy in their own particular circumstances.

For example, participant 13 (who eventually insisted on a referral to the perinatal team and even so became ill but praised the care she received postnatally) was dismayed that the general psychiatrist she saw dismissed the risks that pregnancy posed, considering her history of hospitalisation and family illness:

*‘...the consultant ...told me ...I probably wouldn’t be ill and he didn’t put in place any links with the community, or with the perinatal team. He essentially dismissed me and we subsequently came back because we were concerned that I’d been ...a bit thrown to the wolves...’*

It was pointed out that one would not be denied specialist preconception advice if you had a serious physical condition as often happened to women with BD:

*‘If you had a diagnosis of cancer ...everything is ...given to you on a plate and ...with bipolar it shouldn’t be any different, really.’ P17*

Some women who had been well for many years self-managing with medication and as a consequence had been ‘signed off’ from secondary psychiatric care, experienced



problems getting information from their GP. One woman felt her GP had treated her inadequately by giving her Prozac for what he diagnosed as Postnatal Depression, and then failing to monitor her, issuing repeat prescriptions without consultation while her illness developed into psychosis:

*'I later sued my former GP as the mania had caused such destruction to my business at that time, and the case settled out of court in my favour ...It is very important to be looked after by a Psychiatrist rather than a GP both during and after the pregnancy.'*  
[e-forum]

Women described feeling anxious about how their doctor would react and reluctant to raise the subject of having children for fear of disapproval:

*'I was reluctant to see [my consultant]. In fact when we came to tell him that we were reconsidering [pregnancy] I said to my husband, I'm not bringing it up, you have to say it...because I don't want him to think ... that I'm pushing you into this because I'm some woman, you know, who's obsessed with the idea of having another child.'*  
P12

Many were uncomfortably aware of the power dynamic in the relationship not working in their favour:

*'If I wasn't married to a [health professional] I don't know quite where we would have started from, because within the healthcare system, you're under somebody and basically you're ...at their mercy really.'* P3

This woman was very frustrated with her psychiatrist's attitude to her desire for children:

*'I felt very much that they weren't supportive of me trying to have a baby...I got a lot of negative information and just sort of negative vibes about it along the lines of 'Well that will play havoc with your hormones and you'll never cope' or 'Well you know, that's such a big complicated decision, you couldn't possibly think about making that decision, you know, until you're totally better' and things like that'.*

Due to this unhelpfulness, this couple asked to be referred to a perinatal psychiatrist, but because there wasn't one in their area, they asked to see someone in London. Their psychiatrist reluctantly agreed but then opposed them going for the follow-up appointment:

*'So when we tried to get this referral back to her when I knew I was pregnant, I came up against a brick wall in the local team, and ...they just said 'Well we should never have referred you in the first place because it cost us a lot of money for you to go for the first one, so if you want to see her you've got to pay privately'. P3*

Participant 10 said she stopped asking for information "because I'd been so put off by the psychiatrist", and there were more examples of similar treatment. Encountering a disappointingly negative attitude from doctors was a common theme: one woman saw five different psychiatrists over several years trying to get advice about what to do about Lithium if she wanted to conceive but felt they had "fobbed her off":

*'It took us quite a long time to become proactive ...I think it would have been good...to have some hard facts from them ...rather than... just sort of putting me off really.' P7*

Many women interpreted this unhelpful attitude on behalf of professionals as due to their ignorance in this area of medicine and their reluctance to expose that in front of a patient:

*'Well [sigh] I think a lot of [the psychiatrist's] attitude is to do with a lack of knowledge .... so for example, ...I distinctly had this impression that if you were on Lithium you would basically end up with an unviable foetus who was so badly deformed, just like Thalidomide but worse, you know? ...But when I went to see [the perinatal psychiatrist] and she told me actually what the risk is ... I just thought 'Gosh this risk is on a completely different scale from what I've been led to believe and I think I was led to believe that because it was much more convenient for me to then back off ...' P3*

Some of the several women who had been put on Valproate, despite the NICE recommendation that it should be avoided for women of child-bearing age because of its teratogenic effects, saw this as a reflection of the poor training of psychiatrists:

*'I spoke to him about having children, obviously that came to light because of my wanting to move from Sodium Valproate to Lamotrigine which he should have done anyway according to NICE Guidelines, and he made a comment along the lines of 'Well, being realistic childbirth probably won't happen to you'.*

*P10 [aged 42 at time of interview, who had been enquiring about pregnancy for several years]*

Women viewed the quality of their relationship with health professionals as critical to how confident they felt in their decision-making in pregnancy and postnatally and about the treatment they were likely to receive, and many called for better training on BD and pregnancy - for all maternity and postnatal staff, not just general psychiatrists.

*'I just don't think they have that training...the health visitor and the midwife - I'm not expecting them to really see ...I guess they know how to look for postnatal depression and things like that, but I think the signs are more complicated with bipolar.'* P3

A number of women posted on the e-forum that all health professionals needed better training:

*'More information needs to be available to midwives as well as pregnant women on what to look out for. I believe my traumatic birth triggered off my decline into a depressive episode where I wanted us all to die. I braved it for 7 months but could cope no longer.'* [e-forum - this post was endorsed by three other women]

One woman on the e-community thought mental health training should be extended to Social Services professionals too:

*'I was put in contact with the child protection services when pregnant ...they made life even worse and made me feel like bipolar meant that you automatically would never be good enough to be a parent.'* [e-forum]

It was suggested that women with experience of services could make a valuable contribution to training:

*'I'm ...thinking about service users as trainers ...psychiatric training could include involvement from service users ...because I think they need to hear it from the horse's mouth...' P10*

#### **3.3.2.5.4.2 Continuity of care**

Many women felt their experience would have been greatly improved if there had been more continuity in the health professionals they saw:

*'It's having something like a CPN again, where you've got like a regular [contact], once a month, I don't suppose I need anything more than that...' P15*

This was seen as making a real difference, partly because they could build a trusting relationship with people they saw (and could avoid having to repeat distressing descriptions of their worst episodes of illness), but also to feel more confident that changes in their mood would be picked up:

*'...after the baby's born it will be somebody new ...so I wouldn't expect her to know what to look for, partly because ...she's never met me before so she doesn't know what's normal for me.' P3*

A recently pregnant woman posted on the e-forum that changes to the team caring for her were upsetting:

*'I've been switched to a new mental health team as the early intervention service only work with you for so long. And I had a good relationship with her [her previous contact] I could just text her anytime... And that's much easier ...change is really hard for me and ...I'm also scared about after the birth as I can get worse ...' [e-forum]*

#### **3.3.2.5.4.3 Positive experiences with health professionals: 'the doctors ...were good. It wasn't wrapped up in cotton wool':**

Many women felt they had received excellent advice from the professionals they saw, particularly from specialist perinatal psychiatrists.

*'I think I was told the facts very truthfully, I was treated like an equal and fairly, and I'm glad I know the risks although it's a bit like 'Oh my God I didn't realise' ...I was quite happy with the doctors.'*  
P16 [saw a perinatal psychiatrist]

Others also had a positive experience and appreciated that their suitability to have children wasn't questioned by professionals:

*'It was pretty much a given that I wanted to get pregnant. It wasn't [pause] questioned whether I should or anything like that.'* P15

It was also appreciated when information was presented in a straightforward way:

*'I saw the doctors, they were good, but they were looking at it quite realistically and it wasn't wrapped up in cotton wool, it wasn't fluffy. It was straightforward ...these are your options, we can change your medicine but on the other hand it might not be a good idea; how it will affect the baby in the first trimester...it was pretty matter of fact... and it was really good to have that advice – the more advice I get from professionals would be excellent.'* P16

Some were glad to receive extra attention from services:

*'As it turned out all the monitoring that I had and the care that I received ...was really of the highest quality and I felt very well looked after and supported generally throughout the pregnancy.'*  
P13

For a woman posting on the e-community, finally receiving a diagnosis of BD rather than depression had vastly improved the care she received:

*'The mental health professionals ...advised me to stop taking my medication but did not offer me any other support so I spent the first few months of pregnancy feeling depressed and without hope ... after I was given a diagnosis of bipolar and prescribed quetiapine, I was also given a CPN and started seeing the midwife once a fortnight, so all of a sudden I had lots of support because of a BP diagnosis.'* [e-forum]

Participant 10 (who had been trying in vain to persuade her psychiatrist she should come off Valproate because she wanted to try to get pregnant), was much happier with her care once she was seen by a new doctor:

*'The last time I saw my [new] psychiatrist ...she actually asked me again about pregnancy because she'd seen it on my notes, and she said 'No drug is completely safe but if you do get pregnant Lamotrigine is relatively safe'. So she said, 'Don't let that prevent you from trying to get pregnant'...I felt quite encouraged, because even ...if it doesn't happen ...I walked away thinking 'Well at least you've taken notice of me'. P10*

Participant 11 was also impressed with the care she received. When asked if she had much help after the birth she replied that all the health professionals had been "really great with me", and she was particularly impressed by her Mental Health midwife:

*'I was so grateful to her to explain and educate me that side of things. To say that ...though you might be fine now, postnatal depression exists in normal mothers which you could get and that might take you back into bipolar, that is the scary part.'*

How critical good treatment is to preventing the development of more serious illness, and how much it is appreciated was illustrated by this post on the Bipolar UK e-forum:

*'I was extremely lucky with the support I received during my pregnancy. I was referred to a special team of midwives [and] I had only one midwife who followed me my whole pregnancy ...and she was very aware of what bipolar is. She gave me great advice on postnatal life and answered all of my questions ... I had more scans as well to monitor how the baby was growing and ...was ...also referred to the CMHT and had a fantastic nurse who still visits me. We agreed on a care plan and I saw the psychiatrist a couple of times to decide what medication would be best ...We also had a plan for how to restart medication and I could have decided to breastfeed if I wanted to as they gave me advice on what medication would be best with breastfeeding. I chose not to as I thought I would not be able to cope with the tiredness ... Without the team I was surrounded by I would have probably ended up having to be in hospital. They are the only reason I managed to stay sane.' [e-forum]*

Several women recounted how they had only finally got the information they needed when they had actively sought advice from a specialist perinatal psychiatrist. The difference in satisfaction between women who were able to see a perinatal psychiatrist and those who weren't was noticeable:

*'It really, really helped to go and see [the perinatal psychiatrist] because she just seemed to give it a framework and ...I asked a lot of questions but it felt like she was putting the answers in a context where I felt reassured. So, I feel much, much better now about it'. P3 [woman expecting in a month]*

*'[The] perinatal psychiatrist [came] ...to talk us through all the possibilities and the worries and that was excellent. And that reassured us and gave us, like, an idea of what we need to do and which way to go'. P4*

One woman described seeing a perinatal psychiatrist as:

*'Absolutely ...invaluable because ...to him it was so fundamental to talk about things like sleep, breast-feeding, hospitalization, medication treatment, all of those kinds of things, because he's got the experience which I know other doctors, even all psychiatrists, don't have ...it was very helpful, talking about the percentage risks and the risks at different periods ...you just couldn't get that information from anyone else'. P12*

This opinion was echoed on the Bipolar UK e-forum. One woman said having a preconception appointment with a perinatal psychiatrist was "really helpful and I would recommend for any BP women and definitely worth doing well in advance of trying to conceive". For the benefit of others on the forum, she posted a very detailed, two-page account of her visit to the perinatal specialist (see Appendix 8), for which she was thanked by several other women, for example:

*'That was a really detailed post & has helped me so much. I've always been worried about being referred [to perinatal services] if I was to have another baby. You have eased my fears.' [e-forum]*

### 3.3.2.5.5 Experience of the birth and postpartum period

#### 3.3.2.5.5.1 The birth: 'trying to keep everything manageable'

Women who were expecting a child for the first time, and those who were only considering it as a long-term option, did not consider the circumstances of the birth itself and the immediate postpartum period as of utmost importance. But women who had already given birth or were expecting or considering a second delivery, regarded these as crucial:

*'The birth was very traumatic... and it was very long ...Probably being up for two and a half days is really not good, so clearly one thing is that we don't want a protracted labour and ... I want to make sure that I'm induced if it's dragging on... and also that I do want pain relief ...I want to try as much as possible to ...maximise my chances of making it the least traumatic.'* P12

This woman also considered requesting a Caesarean section (as did two other participants) in an attempt to retain more control and avoid a long labour with no sleep:

*'We contemplated the idea of a caesarean because it's all about trying to keep everything kind of manageable ...but then ...we talked it over...and yes the birth is quicker but ...you've got to recover from major surgery ...and with everything else going on ...we decided that would be the wrong thing to do'* P3

Choice of pain relief was also considered important:

*'I had an epidural which was a huge relief and made the whole experience, you know, much more stress-free than compared to if I'd been labouring in extreme pain because I'm quite prone to anxiety. And I think having a really distressing birth would probably have made things very difficult for me ...as it was, the aftermath was quite difficult anyway.'* P13

One interviewee knew from experience (including a former birth) that she would require electro-convulsive therapy (ECT) so she made arrangements in advance to ensure this was available and wrote an 'advance directive', signed by herself and her



psychiatrist, stipulating that – whatever she said at the time – that is what she should be given:

*'[after I had a miscarriage and made several suicide attempts] the ECT worked brilliantly ...it's the only chance I possible have of not making a serious attempt on my life ... so from the point of view of risk management as well, I need to be in the local hospital where they know me and know that I need it'. P12*

### **3.3.2.5.5.2      The importance of a care plan: 'Now everybody's singing from the same hymn sheet'**

Women found it very helpful if their preferences around the birth were taken into full consideration and recorded in a Birth or Care Plan. As participant 4 said:

*'We did a care plan and I was very happy with [it] ...in the care plan we made sure that if something happens we all know what to do'.*

Having such a plan was regarded as an important factor in relieving women's anxiety about the birth and potentially dangerous postpartum period, as this woman who had become very worried about the lack of help from her general psychiatrist said:

*'I think we now have a plan, and I'm really grateful for [the perinatal psychiatrist]'s summary ... which is incredibly clear, and I've been able to give that to the midwife, a copy's gone to my GP and a copy's gone to the CMHT. So I now feel like everybody's singing from the same hymn sheet ...it's straightforward in some senses, but it hadn't seemed like that before.' P3*

Planning for the possibility of being very ill after the birth was important to many women and some of those who knew there was no MBU in their area were anxious about being separated from the baby and who would look after it. It was also worrying to contemplate returning to the psychiatric hospital where they had had a bad experience previously:

*'[the plan would be] admission to a Mother and Baby Unit, and that's been a big question mark because there isn't one in this area .....the worry before was that I would be sent to the psychiatric hospital I was in before [where] I had a very bad experience ... and wouldn't be able to be with the baby.' P13*

Those women who had experienced problems with their first birth were particularly aware of the need to make a comprehensive birth plan, including this woman who was angry that she had suffered a second postpartum psychosis:

*'If I'd had a care plan I could have been on medication at the end of the pregnancy and just after birth which might have meant this didn't happen at all, [NICE] guidelines...say that you should have a care plan in place at 32 weeks, which I think is too late by the way, because people can have premature babies and imagine if you had a premature baby it would be even worse. How much more likely you are to become ill because you're under all that stress as well?'*  
P2

### **3.3.2.5.5.3      Mother and Baby Units: 'It put my mind at rest to know I wouldn't be split up from my daughter'**

*'[With] my second child, I ...relapsed just after having my boy. I was sectioned a few days after having him and was unable to see him for the first three months of his life. It was like I had been punished for being ill ...Eventually, I was lucky enough to be taken to a mother and baby unit, which allowed me to spend time with him and my daughter and husband, while having 24-hour support. This was invaluable! I couldn't have survived without it.'* [e-forum]

Knowing that specialist care in an MBU was available (if there was a bed free at the time of the birth) was reassuring:

*'At the beginning of my pregnancy I was also visited by one of the nurses from my local MBU and it was explained what would happen if I had to be hospitalised. It really put my mind at rest to know, and to know that I would not be split up from my daughter if I got ill.'*  
[e-forum]

Though most women were keen to be treated in an MBU if possible, it did not suit everyone's needs. One woman, with very severe BD, who was anticipating being dangerously ill if she had a second child and wanted ECT as soon as she showed any signs, went to great lengths to have it specified in an 'Advance Directive' that this was what she needed:

*'A lot of people recommend a Mother and Baby unit, but I think for me the way that things work so swiftly and with needing the ECT, we talked it over with [the perinatal psychiatrist] and decided that it would almost make more sense - if I had to be admitted - to go into [psychiatric] hospital ...because ...I'm, really, really dangerous to myself.'* P12

#### **3.3.2.5.5.4      Suggestions regarding how to improve the experience of services: peer support**

When asked what they would find helpful, many women talked about a desire to speak to women who were or had been in a similar position to themselves:

*'Talking to somebody who is bipolar, who's had a baby or who is pregnant, is going to be invaluable for most people ... just talking about the emotional highs and lows and their feelings and hopes and expectations around pregnancy whilst bipolar, is obviously going to be really valuable.'* P13

Attending a peer support group was also regarded as beneficial:

*'...if there were any self-help groups that I can go to where I can meet people like myself... it's alright the psychiatrist and the social worker telling you, but it's not the same because they haven't been through it, so I'd like to ...go to a group - like I've got diabetes and I go to a self-help group.'* P14

This was echoed by Participant 18, who said she would appreciate

*"a support group ...of women with bipolar who've had children so you'd know ...things to look out for, what to avoid, even talking about whether or not my children could have it ...and what to do".*

Posts on the e-forum concurred, as this woman wrote:

*"it's so helpful to hear from others with BP [about pregnancy]"*

It was further suggested by some that parenting classes would be helpful to improve new mothers' self-confidence and, in one case, to reduce social isolation:

*'I definitely like the idea of parenting classes ...because I could learn loads ...[and] I don't have enough friends, like a social circle...'* P16

A woman who had just had her fourth child said she had asked about workshops to learn about her bipolar and how to manage it better with her family but was told there was nothing available:

*'I asked about all of this and nothing. I also asked what about groups for children who have parents with bipolar? My eldest child could ...do with something like that ...because it does affect everybody.'* P17

## **3.4 Discussion**

### **3.4.1 Key findings**

This is one of the first studies to investigate the factors influencing the decision-making around pregnancy in women with bipolar disorder. Contextual factors together with stigma and fear were major influences on their decision-making as well as their prior experience of services, whilst the strength of their desire to become mothers underpinned all. The factors discussed here are examined in more detail and compared with those identified by general and specialist professionals in Chapter 5's comparative analysis.

#### **3.4.1.1 Contextual factors**

One can see from Table 3.2 that there were numerous contextualizing factors which had a bearing on decision-making: cultural, religious and economic among them. Such factors are also relevant to women without BD when they think about having children but for those with bipolar they may assume a greater significance. For example, individuals with BD are more likely to have difficulty maintaining regular employment (Marwaha et al., 2013) so financial stability can be a significant concern. Being physically and psychologically fit was a concern for some, especially as medication for BD often has the deleterious side effect of considerable weight gain - a research synthesis of 81 articles which included information on antipsychotic weight gain found a mean increase for clozapine of 4.45kg and for olanzapine of 4.15kg (Allison et al., 1999). It is also well-documented that adults with BD are affected by metabolic syndrome at a higher rate than the general population and that women with BD are more likely to be obese than both men with the condition and healthy controls (Baskaran et al., 2014, Zhao et al., 2016).

#### **3.4.1.2 Fear**

Because of the risk of having a serious episode, several women were very frightened at the prospect of being pregnant, especially at the thought that they would have to stop or change medication, and this had been a significant factor in delaying parenthood for many. Some reported searching on the internet and finding inaccurate accounts which had alarmed them and added to their anxiety. Among those who had already had a child, fear of having another postnatal episode was a major reason why they had decided not to have any more, while women who had suffered a postpartum psychosis were particularly scared of this happening again (Robertson and Lyons 2003, Heron et al. 2012). This group were more likely to state that they intended to have no further children as a result, both because of what they themselves would have to suffer and because they did not want their first child to suffer while they were in hospital. Some women were so frightened by the prospect that the pregnancy and/or birth might trigger an episode that they had considered adoption or surrogacy to try to avoid physically delivering the baby themselves.

But those who had thought about this option said they had rejected it because – with their history of mental illness – they doubted they would be ‘allowed’ to adopt even if they had been well for some time. Similarly, when planning for the birth, several said they had considered interventions such as induction and/or a Caesarian section because they feared a long labour with no sleep would add to the risk of triggering an episode. Women who had already had a child were generally far more interested in the ‘mechanics’ of the birth and had firmer ideas on what treatments they wanted to receive; for example, opting to be induced rather than suffer a lengthy protracted labour which would be extremely exhausting and disruptive of her sleep pattern.

Many women in this study were also fearful that they might harm their baby by remaining on their medication. Some women who had been prescribed valproate and subsequently heard that it was teratogenic were very anxious to stop taking it or switch to an alternative. Weighing the chances of damaging their unborn child against the possibility of becoming ill when medication-free was described as extremely difficult and provoked much anxiety. Some women reported that their fear of getting

ill when pregnant or postnatally was greatly exacerbated by being told their pregnancy was officially labelled 'high risk' - a common categorisation used by maternity services to flag up women that might need extra monitoring. The other fear that preoccupied some women was that they would pass on their condition to their children, a concern that was evident in the two studies on attitudes to genetic counselling in people with BD (Peay et al. 2009, Meiser et al. 2005).

#### **3.4.1.3 Stigma**

Stigma was a significant theme from first considering becoming a parent through pregnancy and early motherhood, as was described in Chapter 2's review and elsewhere (Edwards and Timmons, 2005). A systematic review of the literature on BD and stigma (Ellison et al., 2013) found a dearth of research on the subject compared to the literature on stigma and schizophrenia or depression, and so was unable to draw any definitive conclusions except that it had some deleterious effects. This study demonstrates that combining the perception of stigma against having a mental illness with the problem of living up to Western society's concept of the 'perfect mother' exacerbated women's self-stigma as described elsewhere (Lacey et al., 2015). The very fact that women with BD found it so hard to access information on how best to approach pregnancy (and when they asked for specialist advice they were often denied it), was seen by many participants as discrimination.

Women and their families felt that they had to become proactive and investigate for themselves ways of staying well in the perinatal period. This study reports for the first time the ways in which women with BD were actively considering ways of having children without the risks that pregnancy and childbirth poses for them including surrogacy, fostering or adoption. The experience of discrimination in attempts to access fertility treatment was also described (Kissil and Davey 2012). The health professionals with whom they raised these issues were unable to give them information and many women did not know where else to turn. On the question of adopting a child for example, NHS Choices is vague, stating only that: "Mental health issues are given careful consideration and, like physical health issues, do not

necessarily make someone unsuitable to adopt.” (NHS, 2015). But most women interested in exploring this path as a means of avoiding a psychotic episode worried that their mental illness would exclude them from such opportunities (though they didn’t expect the relevant agencies to admit this was the reason).

The other major area where women felt stigmatized was regarding breastfeeding or the ‘failure’ to do so. Women spoke of the excessive emphasis in maternity services on breastfeeding as being “extremely negative” (Participant 4). Hannah and colleagues found a significant association between bottle-feeding and a high EPDS score at the sixth week (1992) and it might be postulated that feelings of failure contribute to this. For new mothers with BD, who were feeling guilty and upset that they couldn’t breastfeed because of the medication they needed to take, pressure to breastfeed added to their pain and produced unnecessary stress and anxiety at a very vulnerable time. A systematic review of mothers’ experiences of bottle-feeding (whether from choice or because of problems experienced) reported similar themes of shame, a sense of failure and worry (Lakshman et al., 2009) but the concerns of women with BD have not been reported previously; such stigma might be associated with a deterioration of a woman’s mental state postnatally.

#### **3.4.1.4 The possible influence of bipolar personality traits**

Anxiety over their capability to be a ‘good’ mother was exacerbated by Western society’s media-driven focus on the need to be a “Super Mum”, and many high-achieving women with BD felt pressured to demonstrate that their mental illness did not disqualify them from being mothers, fearing that society regarded them as incapable of fulfilling this role. This resulted in acute feelings of guilt (Edwards and Timmons, 2005, Davies and Allen, 2007), and a perceived need to go to extraordinary lengths to ‘prove themselves’ (Montgomery, 2005), as was described by some of my study participants (section 3.3.2.2.6). Anxiety over their capacity to be the excellent mother they had hoped to be may be due to personality traits associated with the condition. There is some evidence from a review of the neurobehavioural aspects of affective disorders by Depue & Iacono (1989) and cross-sectional studies in the



Personality Traits and Behavioural Approach System literature (Kim et al., 2012, Depue and Collins, 1999) which suggests that people with Bipolar 1 are particularly goal-orientated compared to controls and those with depression (Lam et al., 2004), and score highly on 'Achievement striving' Personality Trait measures (Kim et al., 2012). This group may have been disproportionately represented in my sample as this trait is likely to be associated with high educational achievement; a notable characteristic of my interviewees, 67% of whom were graduates.

The Behavioral Approach System (BAS) model is a biobehavioural system that regulates approach motivation and goal-directed behaviour to attain rewards (Gray, 1994). It has been linked with a reward-sensitive neural network, involving dopaminergic projections from the limbic system to the frontal cortex (Depue and Iacono, 1989). Considerable evidence supports the BAS model of Bipolar Disorder (Alloy et al., 2008, Meyer et al., 2001, Salavert et al., 2007, Urošević et al., 2008). According to this model, vulnerability to Bipolar Spectrum Disorders is reflected in an overly sensitive BAS that is hyper-reactive to goal- and reward-relevant cues (Alloy and Abramson, 2010). The cognitive styles of individuals with BD are characterized by BAS-relevant themes of goal-striving, perfectionism, and self-criticism (e.g., Alloy et al., 2009, Lam et al., 2004). Also, compared to healthy controls, individuals with BD exhibit increased relative left frontal cortical activity as assessed by electroencephalography (EEG), a neurobiological indicator of BAS sensitivity and activation, both in the resting state and in response to anticipation of rewards (Harmon-Jones et al., 2008) and frustrations (Harmon-Jones et al., 2002). Moreover, on functional magnetic resonance imaging (fMRI), compared to healthy controls, both euthymic and manic bipolar individuals display increased activation of the ventral striatum and lateral orbitofrontal cortex, which are part of the corticolimbic circuit subserving reward-related processing (Bermppohl et al., 2010, Nusslock et al., 2014). A review of this evidence (Johnson et al., 2012) reported that individuals with Bipolar 1 obtained higher scores on the Sensitivity to Reward scale (Torrubia et al., 1995) than did healthy controls.

According to Johnson and colleagues (2012) 'incentive sensitivity' in bipolar disorder seems to be related to two processes: a tendency to invest in difficult-to-attain goals

and ‘an over-reactivity to cues of goal progress versus thwarting’, i.e. they tend to react disproportionately when they either attain their desired goal or they fail to attain it (Johnson et al., 2000).

Considering this personality trait in the context of becoming a mother while coping with a mental illness, it might be suggested that Western society’s current emphasis on being a ‘Super Mum’ could exacerbate an existing tendency in a woman with BD to strive for perfection in the role of mother. That danger not only relates to pushing herself too far (and compromising her sleep and energy levels) but also could contribute to feelings of failure if she is unable to live up to unrealistically high expectations, which in turn could feed into dangerous feelings of being a failure whom her child would be better off without. This theory has not been tested, nor is it mentioned in the literature, but I suggest it as a possible psychological contribution to understanding women with BD’s extreme vulnerability to illness in the immediate postnatal period which might be worth investigating. If a woman is temperamentally predisposed to strive for perfection, the added societal pressure to be a ‘perfect mother’ may contribute to an escalation of her illness. Perhaps this is something for services to be aware of: for example, extreme efforts to present a ‘perfect home environment’ (e.g. cleaning the house from top to bottom and producing cakes for visiting health professionals); working out to get back to ‘perfect weight’; appearing particularly well-groomed and so on. In order to achieve this they might be getting up extremely early and getting into a cycle of over-stimulation which could in turn contribute to them becoming manic or psychotic. Counselling for women with BD preparing for motherhood together with peer support might be a useful way of highlighting this danger of over-perfectionism and encouraging women to be realistic in their expectations and prioritise sleep in order to stay well and capable of caring for their infants.

#### **3.4.1.5 Social support**

Most women in this study were aware of the extra support from family and friends that they would need. Those with partners were very keen to involve them in the

decisions to be made, though some expressed concern that they weren't truly aware of the possible severity of an episode if they chose not to take medication. Particularly women whose partners had only known them when well expressed fears that the stress of coping with a severe episode plus a new baby would put an intolerable strain on their relationship, and unfortunately there is evidence that the rate of marital breakup is higher after a postpartum psychosis (Blackmore et al., 2013). Generally, those women who were single and did not have much support from family and friends were more accepting of the need for more professional oversight to help them cope but some still This factor was usually related to how much they feared Social Services' involvement as a new mother with no social support may need more monitoring and would feel under greater pressure to prove she could care for her child (Sands, 1995, Ackerson 2003).

#### **3.4.1.6 Relationships with health professionals**

Central to women's experience of decision-making around pregnancy and childbirth was their access to information and reliable advice, so their interactions with health professionals were crucial to this (Heron et al., 2012b). The sub-theme 'Bashing my head against a brick wall' illustrated the serious difficulties many women experienced when trying to get information from GPs and even general psychiatrists. They often felt stigmatized as potentially 'mad, bad mothers', while some were aware that the professionals themselves lacked the knowledge to answer their questions. The way in which the risks were presented and the language used was recognized as important: women didn't want to be overly scared by what might go wrong but equally they didn't want it "wrapped up in cotton wool". Women who were given the opportunity to consult a specialist perinatal psychiatrist (as recommended by NICE (2014) were far more likely to be satisfied or pleased with the information and assistance they received: one described it as "invaluable" (Participant 12). Unfortunately, many women reported receiving little or no information from their GPs and several even found that their (general) psychiatrist was unhelpful, as reported elsewhere (Heron et al., 2012b, NICE, 2012). It was noteworthy that when someone posted a detailed description of her positive preconception consultation with a perinatal psychiatrist on

the Bipolar UK e-forum, several women went online to thank her profusely for the information as they had been unable to find it elsewhere (see Appendix 8).

#### **3.4.1.7 Continuity of care**

The need for continuity of care was another frequently raised issue, not only because of the stress involved in having to repeat accounts of very distressing episodes of illness from the past to a string of different professionals, but also because it would aid the development of a trusting therapeutic relationship. The desirability of continuity of care has been recognised by NICE (Kendall et al., 2014). It was seen as particularly important by women with BD because identifying changes in mood are crucial to identifying the escalation of their illness and this is obviously much more difficult if they are seen by a series of different professionals. Early identification of signs of illness is also something that could be improved by better training for health professionals. Many women felt that maternity staff were ignorant about BD and held stigmatizing views of them as mothers. Improving training on BD for all maternity workers and midwives and health visitors in particular was called for as a way of tackling this, as was also reported in Chapter 2's review of studies with women with SMI, but it was women's experience that even among mental health professionals, ignorance of the relationship between BD and pregnancy was widespread. Women were disappointed when general psychiatrists displayed stigmatizing attitudes towards them, sometimes disparaging their ability to be good parents, and it was suggested that involving service users in professional training could help with this. Repeatedly women said they wanted to be referred to a specialist perinatal psychiatrist who had the expertise and experience to advise them (3.3.2.5.4.3: Positive experiences with health professionals).

#### **3.4.1.8 Peer support and parenting assistance**

The other way in which women with BD felt they would better cope with their anxiety around pregnancy and childbirth was if they could have some peer support. There is some evidence attesting to the value of peer support for people with mental illness,

for example Chinman and colleagues (2014) conducted a review of peer support services for individuals with SMI and found that such services were better able (than professional staff) to reduce inpatient use and improve a range of recovery outcomes, although one of the 20 studies included found a negative impact. However, a systematic review and meta-analysis of RCTs of peer support for people with SMI conducted by Lloyd-Evans and colleagues (2014) found some evidence that peer support was associated with positive effects on measures of hope, recovery and empowerment but that there was little or no evidence of positive effects on hospitalization or overall symptoms. Limited research has been done specifically on women in the perinatal period; mostly focussed on whether peer support reduced postnatal depression (PND). Dennis and colleagues (2009) trialled a telephone-based peer support intervention with 701 women identified in the first two weeks postnatally as at high risk of PND. At 12 weeks, 14% of women in the intervention group and 24% in the control group had an Edinburgh postnatal depression scale score of >12 and over 80% of the intervention group were satisfied and would recommend this support to a friend. In the current study, women talked about a desire to speak to others who were or had been in a similar position to themselves (see section 3.3.2.5.5.4). Some women were keen to receive such support as new mothers, in particular from other women with BD rather than in a generic mental health setting, a desire also reported by Venkataraman and Ackerson (2008). It was suggested by some that parenting classes would be valuable as some new mothers were worried about their condition affecting their ability to parent consistently and felt they and their children would benefit from some extra help (Reupert and Maybery, 2007).

### **3.4.2 What this study has added to the existing literature**

This study has added to the literature in a number of ways. Firstly, it is the first study to look specifically at the experiences and views on pregnancy and motherhood of women with a diagnosis of bipolar disorder. The systematic review was very heterogeneous and located only two papers which were solely concerned with bipolar. Wilson and Crowe (2009) used critical discourse analysis to examine the views of four women and one man on parenting with BD in New Zealand; they did not attempt to interrogate the issues around preconception decision-making, or the approach to decisions during pregnancy or in the immediate postnatal period when a recurrence of illness is most likely to occur.

Similarly, the other BD paper included in the review, Venkataraman and Ackerson (2008) which interviewed 10 mothers with BD in the US, was solely concerned with parenting with BD. The current study, while including data about parenting with BD in so far as it affected participants' desire or otherwise to consider having children, was more focussed on the decision-making process in the preconception and perinatal stage (defined as up to one year post-birth). For example, some women expressed doubts about their ability to be a good parent and some on the e-forum said this was the main reason why they had decided not have children. This is a specific period of women's lives when their BD can have critical significance, and when they will be interacting with many services that will only see them at this time, such as midwives, obstetricians and Health Visitors, as well as specialist perinatal psychiatrists if they are able to access that service. Therefore publication of the analysis of the data from the 21 women interviewed and 50 women who responded via the internet forum was the first time these women's views on perinatal decision-making have been recorded in the research literature. As this is a time of both significant risk for women with BD (as bipolar carries the highest risk of being triggered in the perinatal period of any mental disorder), and a time of increased contact with services, I believe it merits attention.

It is also worth noting that one of the major distinguishing characteristics of BD is that people with this diagnosis are the only group under the umbrella of Severe Mental Illness that experience mania and the particular way in which this might impact on pregnancy and the perinatal period had not been examined before this study. Women

with BD interviewed in Venkataraman and Ackerson (2008) spoke of some of their bipolar 'personality traits' being a strength when parenting, so I was interested to discover whether women in my sample regarded their condition as in any way positive during pregnancy and one year post birth. On this subject, women in my sample were mostly concerned about the close link between lack of sleep and bipolar mania (Lewis et al 2018); a connection which is particularly pertinent to BD around the time of childbirth and which prompted some women to consider feeding their infant with a bottle rather than breastfeeding

It was noticeable that fathers or partners were barely mentioned in the papers included in the review in Chapter 2. As postulated previously, this was probably due to the large number of single women in the studies (see 2.2.2.2.1.4 'Isolation'). In the review, it was only women interviewed in the studies focused on postpartum psychosis who talked about their partners and the support they gave them, so it is interesting that this was a more prominent theme in the current study, with many women describing how critical their partner's input was to the decision-making process (3.3.2.2.7.1 'Importance of partner's attitude' and 3.3.2.4.5 'Threat to relationships').

### **3.4.3 Strengths and limitations**

Other strengths include a sample with representation of women at different stages in their journey through or prior to motherhood, from different ethnic backgrounds and from different types of mental health services (community-based, hospital inpatient and MBU). However, a relatively high proportion of interviewees were educated to degree level or above (67%), which might partly be explained by half of the sample being recruited via preconception clinics which tend to see a disproportionate number of educated women from higher socioeconomic groups who actively seek specialist advice on pregnancy. The novel service user-led design employed in this study was particularly appropriate for this relatively unexplored area of research to ensure the development of user-relevant research questions and to counteract reluctance to disclose potentially upsetting experiences. However, my position as a service-user researcher who has had similar experiences to my participants and who volunteers for

related charities, could be viewed as both a strength and a limitation. The five interviewees who were recruited via Bipolar UK did know me as a trustee and co-facilitator of 'Bipolar and pregnancy' workshops, so it is necessary to acknowledge the possibility that this might have influenced them in terms of social desirability response bias, which must also be taken into account for those referred from perinatal psychiatrists in the South London and Maudsley area as my principle supervisor is a perinatal psychiatrist in that trust. For example, three of the five interviewees in SLaM who were aware that my supervisor was in the perinatal psychiatry service there were positive about the superior treatment they received from the specialist service. Whilst being mindful of this possibility, it was useful to investigate whether this trend was corroborated by the majority of interviewees who did *not* know her, and further triangulate that data with the opinions expressed in the e-forum where no such social desirability bias existed due to the participants' anonymity and dispersed localities. An examination of this point confirmed that all women, interviewed or online, who described having consulted a specialist perinatal psychiatrist, reported satisfaction with the encounter and made positive comments about the experience.

As other studies have found, being a service user researcher was an advantage in terms of recruitment and obtaining rich data (Ennis and Wykes, 2013) but may have affected the interpretation of the data. I made efforts to guard against researcher bias by having an independent researcher conduct a parallel analysis of data and, in a further attempt to enhance confidence in the findings, methodological triangulation was employed (Flick, 2004) as described in Methods (3.2). Two different methods of collecting data – direct in-depth interviews and internet discussion where responses were delivered in written form – were employed and I felt these two sources complemented each other and strengthened the validity of the findings (Seale et al., 2010). Though the questions posed on the e-forum 'Bipolar and Pregnancy' stream by me as a researcher were based upon the interview topic guide, the fact that the responses were delivered in written form and with no opportunity for a dialogue rendered them intrinsically different and removed the possibility of respondents being influenced by the presence of the interviewer.

The socio-demographic characteristics and geographical location of the 50 women



who responded to my post were not known (members of the forum are registered but use anonymous 'tags' or pseudonyms). The e-forum is accessed through the Bipolar UK website and all participants have to register with their personal details. According to registration figures for 2016-17, there were 16,909 people registered on the forum, of whom 11,613 were female (69%). The numbers in each age group were as follows: Under 16: 17; 16-25: 1,575; 25-35: 4,455; 35-45: 4,947; 45-55: 3,762; 55-65: 1,597; over 65: 490. Data on ethnicity or socio-economic class was not collected so this was a limitation, as was the fact that participants self-identified as having a diagnosis of BD. Many on the e-forum gave detailed accounts of their own experience of pregnancy decision-making which included deciding against having children because of their BD, a viewpoint impossible to access via the sample interviewed. Other comments also provided valuable new perspectives leading to new themes that had not emerged from the qualitative interviews, for example, stigma encountered when seeking treatment for infertility.

The methodology employed to elicit the internet data was also more robust ethically than is often the case with web-based qualitative research (Rodham and Gavin, 2006). Most qualitative researchers collecting personal accounts of phenomena extract their data without the knowledge of the people who have posted it on the internet, so it could be said that the authors of the narratives could not foresee or give explicit permission for their personal stories to be reproduced in a research paper (for example in the paper by Engqvist et al. (2011) described in Methods section 3.2.2). Engqvist's justification was that "since personal narratives on the Internet can be read by anyone, informed consent is not required ...as there is no reference in this article to information that might allow the women to be identified" but such methodology is controversial (Rodham and Gavin, 2006). By contrast, in the present study prior consent was obtained from women taking part by clearly stating at the top of the thread 'Bipolar and Pregnancy' that the research was "approved under Study Ethics code:11/LO/1469)" and that posts "could be used within the project on an anonymous basis". Also, by deliberately entering a forum specifically aimed at the target population (women with BD) and requesting responses based on particular questions, the data gathered was more specifically focused on the hypotheses of the study but

also allowed participants freedom to express their views in a freeform way on any related topic. The internet arm of the study was also a valuable means of including the views of women who had deliberately chosen not to have children because of their BD (such women would not be attending preconception clinics or pregnancy advice workshops which were the two main sources of recruitment for interview). Only one woman interviewed said she would not be having a second child, whereas 13 (26% of respondents) wrote in their forum posts that they had decided against becoming pregnant, including 6 (12%) who said they had decided against having any children because of what they saw as the risks due to their illness.

#### **3.4.4 Clinical and research implications**

Results of the combined thematic analysis of the qualitative interviews and e-forum texts highlight the complexity of decision making around pregnancy for women with BD and the anxiety this can cause. Women described how much they wanted good advice to help them make difficult choices over medication, the conduct of labour and birth and treatment in the postpartum period, and how 'frustrated' and 'angry' they were that such information and support was often denied. This emphasizes the need to implement nationally the recommendations of NICE (2014) which recognize the need for specialist up-to-date advice, preferably before a woman becomes pregnant. The expressions of fear by women with BD about taking medication in pregnancy are in line with previous research indicating a high level of maternal anxiety over the teratogenicity of medications for depression in pregnancy (Ververs et al., 2006, Einarson et al., 2001). Women in this study suggested information on the pros and cons of different treatments should be delivered in a comprehensible, jargon-free way, with a compassionate understanding of the potential it has for provoking greater anxiety in the recipients, who were understandably hoping that they would have a relatively 'normal' pregnancy and birth. Einarson and colleagues (2001) demonstrated that a majority of women with depression resumed taking their medication while pregnant after receiving well-informed counselling on the subject; it would be useful to conduct a similar study with women with BD and discover what effect, if any, there

was on outcomes. Indeed, recent research found that perinatal suicides were associated with a lack of prescribing of medication (Khalifeh et al., 2016). An individualized risk benefit analysis is therefore needed for women with BD and other serious affective disorders (NICE., 2014).

Evidence from this study supports the case for research into the effect of high quality preconception counselling for women with BD. It would be helpful to establish how much it influenced medication decisions and whether it reduced the rate of relapse in this population. As yet only a service evaluation of the outcome one year after a preconception consultation for women with BD has been published (Wieck et al., 2010). In a sample of 32 women attending a preconception clinic in Manchester, the clinic recommended continuing the same medication in 9 cases (28.1%), stopping medication in 4 cases (12.5%), and switching to different agents in 19 cases (59.4%). The authors reported that this advice took into account illness severity, adverse medication effects on the child and patient preference. Of the 26 patients for whom data was available at follow-up, 5 (19.2%) developed a DSM-IV episode, mostly in the first 6 months after the consultation (n=4) and were treated as outpatients. In all of these cases, pharmacological recommendations had been followed, but in only 1 had medication been stopped. A longer longitudinal study employing a matched control group without access to specialist preconception advice would give insight into the effectiveness of such clinics. There has also been little research on the effect of a woman with BD's illness on her partner in the perinatal period, though a review of 20 studies on paternal postpartum depression found it to be a significant problem, ranging from 24% to 50% among men whose partners were experiencing postpartum depression compared to rates of 1.2% to 25.5% in community studies (Goodman, 2004).

This study highlighted the serious consideration many women with BD give to requesting a delivery by Caesarian section in order to have greater control over the birth and avoid the stress and sleep deprivation of a protracted labour. As yet no research has been conducted on whether electing to have a Caesarian delivery reduces the risk of postnatal illness for women with BD, though the long-term risks to the child

(including links to obesity, asthma and type 1 diabetes) of having a C-section have been highlighted (Zhou et al., 2015). Sleep is extremely important for people with mood disorders (Benedetti and Colombo, 2011) and particularly for women with BD: Saunders and colleagues found women reported poorer sleep quality than men and poor sleep quality predicted worse mood outcome in BD (2015). Research is needed on the role played by sleep deprivation in the onset of postpartum psychosis in women with a history of BD.

Some women's fear of Social Services taking their child away is an issue that has been raised in many studies on perinatal mental disorders (Megnin-Viggars et al., 2015, Dolman et al., 2013). Anxiety and stress caused by such fear could be detrimental for the baby in utero (Beydoun and Saftlas, 2008) as well as for the mother, and health professionals could potentially alleviate some of the distress by raising the subject themselves (as most women fear introducing it) and reassuring women about how rarely babies are removed (Howard et al., 2004) or how, in some circumstances, Social Services can be a source of support. An evaluation of the involvement of Social Services in the perinatal period and its effect on outcomes would be a useful addition to the literature. Peer support groups - preferably aimed at mothers with BD (as also proposed in the study by Venkataraman and Ackerson (2008), and tailored parenting classes were suggested by participants as ways of improving their child-rearing abilities, both interventions which are worthy of evaluation.

Maternity services could mitigate the problems faced by women forced to bottle-feed their infants by adopting a more sensitive and non-judgmental approach to mothers in this situation. As suggested by nurse educator Professor John Mozingo: 'mothers should be reassured that bonding, attachment and infant health are not irreversibly damaged [by bottle-feeding] and the quality of their mothering should not be questioned because of the feeding method chosen' (Mozingo et al., 2000). They might also encourage mothers to use methods to enhance bonding such as 'skin-to-skin' contact (Feldman and Eidelman, 2003) and maintaining eye contact while bottle-feeding (Carlsson et al., 1978). Despite the emotionally taxing dilemmas faced when contemplating pregnancy and the challenges of being a mother with mental illness,

this study also confirms the enormous importance women with BD attach to having children and how some felt motherhood had helped them to cope better with their condition, consistent with the views of other women with SMI (chapter 2). Finally, criticism was often directed at psychiatrists by women in this study, so in the next chapter, the views of health professionals – specialist and non-specialist – were sought to better understand the roles of all parties in the decision-making process.

Results from this study have been published: Dolman, C., Jones, I.R. and Howard, L.M., 2016. *Women with bipolar disorder and pregnancy: factors influencing their decision-making*. British Journal of Psychiatry Open, 2(5), pp.294-300.

[Copy attached in back of bound version's folder].

## **4 The views of health professionals working with women with bipolar disorder: how do they approach advising them on pregnancy decisions?**

### **4.1 Introduction and aims**

Much of the data gathered from women in Chapter 3 concerned the advice they received – or did not receive – from health professionals, so it seemed important to gain the perspective of professionals themselves. The main reason for this was to explore which factors health professionals believed influence women with bipolar disorder when they're considering pregnancy; what did they perceive to be the critical information women and their partners want, and what was the best way to conduct preconception counselling sessions? In Chapter 2's systematic review of the views of health professionals caring for women with SMI which analysed 8 studies, only 10 psychiatrists were included. As it is generally a psychiatrist who is involved in assisting women with BD to make decisions about pregnancy and childbirth, I considered it useful to explore their attitudes to the process. It was also valuable to hear from professionals what issues came up for them in this situation as well as for the women or couples.

I elicited these views via two different qualitative methods. Firstly, I conducted a focus group at the biennial meeting of specialist perinatal mental health professionals, the Marcé Society, held in Swansea in September 2014. Secondly, I conducted interviews, mostly by telephone, with general adult psychiatrists (described under 4.1.2). Methods and results from these studies are reported separately but discussed together (4.1.4).

## **4.1.1 Specialist Perinatal Mental Health Professionals**

### **4.1.1.1 Methods**

#### **4.1.1.1.1 Focus group design**

The use of focus group methodology has several advantages. It combines the strengths of semi-structured interviews with the impact of group interaction to stimulate debate and generate a variety of views (Morgan, 1996). Also it was practically more feasible to gather the views of 11 participants from different parts of the UK in the same place at the same time. However it also has limitations: the researcher has less control and it is possible that some individuals might dominate the group discussion and so discourage others from expressing their views (Krueger and Casey, 2000).

#### **4.1.1.1.2 Ethical Approval**

This study received ethical approval from the NRES Committee London - Camden & Islington (11/LO/1469).

#### **4.1.1.1.3 Recruitment strategy**

Participants were recruited via the internet 'ListServ' of the United Kingdom and Ireland division of the International Marcé Society (members join because of their professional interest in perinatal mental healthcare). The inclusion criteria were: attendance at the conference, experience of treating women with BD in the perinatal period and willingness to take part (see Appendix 8 for letter of invitation). I wrote to participants with further details and to confirm attendance. This was a purposive sample to try to achieve a broad representation of professional groups so I also approached GPs via the Royal College of General Practitioners but they were unable to help with recruitment, and personal approaches to individual GPs were also unsuccessful.

#### 4.1.1.1.4 Development of Topic Guide for Discussion

A topic guide for the focus group was developed based on the themes that had arisen from the qualitative study conducted with women reported in the previous chapter and in collaboration with my supervisors, both of whom are perinatal psychiatrists (Figure 4.1 below).

***Figure 4.1: Professionals' topic guide***

<p><b><u>Professionals' topic guide</u></b></p> <ol style="list-style-type: none"><li>1) What factors do you think are the most important to discuss with women with bipolar when they're considering pregnancy?</li><li>2) To what extent do you think background factors play a role?</li><li>3) What else is relevant to their decision-making?</li><li>4) In terms of medication, what do you think needs to influence their decision-making?</li><li>5) What are the barriers and facilitators to frank discussion?</li><li>6) Who do you think women should have these discussions with? <a href="#">[i.e. which professionals...]</a></li><li>7) What do you see as your role in the decision-making process?</li><li>8) Do you know of any information resources to which you could signpost them?</li><li>9) Do you know of any sources of support in making decisions on this subject that you could signpost them to?</li><li>10) Is there anything that might be useful to assist the decision-making process? [If anyone says decision aid] then what should it encompass? What would be the best means of delivery? <a href="#">[e.g. leaflet, video, web-based interactive module]</a></li><li>11) Is there anything else you think is relevant about these issues which we haven't discussed?</li></ol> <p>[General adult psychiatrists were also asked how often they had these sorts of discussions with women with BD and the timing of such conversations]</p>
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#### **4.1.1.1.5 Study setting**

Study site: The International Conference of the Marcé Society (for professionals working in perinatal mental healthcare and research), held at Swansea University, Wales, which took place 10-12<sup>th</sup> September, 2014. The focus group was held in a meeting room at the university during the lunch break of the conference on 11<sup>th</sup> September 2014 (sandwiches and refreshments were provided).

#### **4.1.1.1.6 Focus Group procedure**

I acted as an observer and gave a general introduction explaining the purpose of the focus group, confirming that no members would be identified and only anonymized direct quotations would be used in the analysis. Facilitator Dr. Kylee Trevillion, an experienced qualitative researcher, then detailed some ground rules (Appendix 8). Before the discussion began, the Chair (a senior perinatal psychiatrist) asked all group members to introduce themselves. The session lasted 47 minutes.

#### **4.1.1.1.7 Analysis**

The focus group discussion was audio-taped and transcribed verbatim by an independent transcription service approved by the IOPPN. The transcript was read several times and an initial coding frame developed. An independent researcher (Dr. Emmeline Lagunas Cordoba) analyzed a proportion of the transcripts separately and then we met to compare results and resolve differences. After achieving a 90% inter-rater agreement the results were discussed with my supervisor (LH) to achieve consensus.

#### **4.1.1.2 Results**

##### **4.1.1.2.1 Participants**

11 participants took part, mostly perinatal health professionals with considerable experience, comprising:

- 4 perinatal psychiatrists
- 1 perinatal/general psychiatrist
- 1 obstetrician with a special interest in mental health
- 1 senior midwife with perinatal mental health experience (National Lead for Midwifery Education)
- 1 specialist perinatal clinical psychologist
- 1 psychologist with a special interest in the perinatal period
- 1 community mental health nurse (Perinatal Lead for Community Mental Health Team, CMHT)
- 1 specialist Health Visitor (trainer of Health Visitor Perinatal Mental Health Champions)

All participants were health professionals currently working in the UK National Health Service (all based in England and Wales). Ten were female, one male; 9 were white British, 2 Asian British. Two were based in Wales, 4 in London and the remainder in other parts of England.

##### **4.1.1.2.2 Themes**

The thematic analysis of health professionals' views on the factors influencing decision-making around pregnancy for women with BD generated two superordinate themes: *Professionals' perspectives on women's anxiety over decision-making*, and *the decision-making process*. The first overarching theme encompassed: fear of damage to the baby; fear of relapse, fear of Social Services and apprehension over stigma. The second overall theme *the decision-making process* included: communication; professional concerns peculiar to the perinatal context; appreciating individuality and advance planning. The themes and sub-themes are shown in Table 4.1

**Table 4-1: Specialist perinatal professionals' views on pregnancy decision-making for women with bipolar disorder: themes and sub-themes**

Professionals' perspectives on women's fears				Professionals' perspectives on the decision-making process			
Fear of damage to baby	Fear of relapse	Fear of Social Services	Fear of stigma	Communication	Professional concerns	Individualization	Advance planning
'can be overwhelming'	'risks of not medicating ...just as bad'	'so frightened they'll be referred to Social Services'	'they might feel very stigmatized + very anxious'	'Need for reassurance'			
Medication 'questions people don't ask often around sheer terror'				Research uncertainty 'very important to be honest'	High stakes: timing of advice 'the worry is ... we don't see women at that key point'	Importance of personal history 'what's the fallout if she gets ill?'	Need for specialist advice from perinatal psychiatrist due to 'complexity' and 'challenges'
Genetics + impact on parenting 'they can be crippled with guilt and worry'				Raising difficult issues 'mention the unmentionable'	Danger of exacerbating anxiety 'such a dilemma ... I really struggle with the numbers'	Personal information preferences and individual perception of risk	Co-ordination between services 'need for liaison and integration'
				Discrepancies with other sources of info: internet and professionals	Danger of diagnostic overshadowing 'need to think about physical issues'	Cultural considerations 'understanding the family and the cultural pressures'	Detailed plan in place 'as early as possible'
				Coping with volume of information		Degree of partner involvement 'both should buy into plan'	Obstetric pathway 'she needs to know what to expect'

#### **4.1.1.2.2.1      ‘Sheer Terror’: Professionals’ perceptions of women’s anxiety**

There were four major sub-themes in this category: fear of harming the baby whether via medication, genetic inheritance or poor parenting; fear of relapse, fear of Social Services removing the baby and fear of being stigmatized.

##### **4.1.1.2.2.1.1      *Fear of harming their child***

Group members reported three main strands to this theme: a terror of the teratogenicity of some medication; a concern over the genetic inheritance they were passing on, and lastly whether the impact of their illness on their parenting abilities would have a lasting detrimental effect on their child.

##### **4.1.1.2.2.1.1.1      *Medication***

A perinatal psychiatrist described the “huge anxiety that goes alongside the medication”. Another described how women were often so frightened of what they might be told that they held back from asking about it:

*‘I do think the questions that people don’t ask are often around sheer terror. I think that my experience is that the ultimate core symptom of fear is around damaging the child.’*

Others agreed:

*‘It can be overwhelming and women will not take anything because they’re so frightened that whatever they do ...they might do something terrible to their baby’.*

##### **4.1.1.2.2.1.1.2      *Genetics and impact on parenting***

A perinatal psychiatrist who mainly saw couples for preconception advice said that it was uncommon for them to raise the issue of genetics at that stage. But the perinatal psychologist in the group said postnatally her experience was quite different:

*'I'm more likely to work with women when they're recovering from their episode and they have a new baby and that's a time when they really do bring it up and they express a lot of anxiety about all sorts of things. Genetics, but also how their mental health problems might have influenced their care of the baby ...they are very anxious ...and they tune into all the messages that they see in the media about mental illness and parenting and then they can be crippled with guilt and worry'.*

The Health Visitor in the group agreed:

*'I find they are really worried about the impact afterwards and they will attribute all manner of things with their child as being a direct result of their illness, and they will not consider the normal process of what a baby's like ...or what the future might hold'.*

#### **4.1.1.2.2.1.2      *Fear of relapse***

A psychologist who worked with women on a Mother and Baby Unit said she was very concerned that, when discussing preconception options, women weren't given a realistic enough picture of what might happen if they stopped their medication and relapsed as it might be worse for her and the baby than continuing to take it:

*'the counter argument is how would they feel if they had a relapse during their pregnancy or immediately post-birth and having seen many, many women who are pregnant being restrained or put in intensive care, it's traumatic, it's horrific. I'm not suggesting that you alarm them, but is there a way of communicating that there are also risks of not medicating and that that could be just as bad?'*

A perinatal psychiatrist agreed:

*'It's a very, very important part of the discussion because I think people often come very worried about what would be the effects of medication but that's part of the weighing up of ...the effect of deciding to come off your medication and what is the evidence we've got for that and what's the risk in that individual woman.'*

She added that *'people who have had a previous post-partum psychosis are often really terrified of that happening again'.*

#### 4.1.1.2.2.1.3 ***Fear of Social Services***

Group members described how scared many women were of losing custody of their child:

*'My experience is it's the medication and is someone going to say I shouldn't have care of my baby - they're the two main worries that people come with'.*

The perinatal psychologist in the group suggested preconception counseling should always address the issue of possible Social Services' involvement:

*'I know that a lot of women are just so frightened that if they disclose anything they'll instantly be referred to Social Services, and ...the reality is that some of them actually will need referral to Social Services. So I suppose something about ...having an honest but hopefully containing and reassuring discussion about those sorts of issues might be important.'*

A perinatal psychiatrist agreed that there was a need for honesty and clarity when dealing with this issue.

*'I think that's very important ...that's a huge anxiety and goes alongside the medication ...[that] someone is going to say I shouldn't have care of my baby.'*

#### 4.1.1.2.2.1.4 ***Fear of stigma***

The perinatal psychologist also raised the issue of stigma:

*'I'm also aware that women might feel very stigmatised and very anxious about who they tell about their mental health problems'.*

This was met by nods and murmurs of assent around the table.

#### 4.1.1.2.2.2 Professionals' perspectives on the decision-making process

##### 4.1.1.2.2.2.1 **Communication**

As well as tailoring the content of information to individual patients, professionals giving preconception advice were extremely conscious of the need to describe the risks of different choices in a comprehensible way, as they knew it was difficult to take in so much complexity. It was recognized that developing a good therapeutic relationship was "vital":

*'it's an important conversation to have with women in terms of ...developing your relationship with them and [building] trust.'*

##### 4.1.1.2.2.2.1.1 **Reassurance**

Because of this complexity and the emotional content of the matters under discussion at a preconception appointment, it was suggested that a major part of the professional's role was to present information in a clear and compassionate way that would reassure rather than alarm.

*'Most people ...over-estimate the effect, whether it's a genetic effect or whether it's the impact that being unwell around the time [of birth] has - that it's somehow going to devastate their children's behaviour. I think reassurance is a big part of what ...I do.'*

One way of presenting the risk ratios in a less alarming manner was to compare the situation to making similar decisions about physical conditions:

*'I often say to women that if they're taking some treatment for a physical health problem, they might not have such angst about it and that ...actually they should think about it in a comparable way. If they had diabetes and were on insulin ...they probably wouldn't have such anxiety and guilt about exposing babies to very, very tiny risks.'*

Another perinatal psychiatrist highlighted the need to facilitate decision-making rather than make the decision for the patient:

*'I am usually very clear (I hope) that it's the woman's decision and I am there to help provide information and think through the issues, and I think most women seem happy with this. A few women still seem to say "I'll do whatever you think is best doctor..." and I try to explain that there is no right or wrong decision.'*

Her colleague agreed:

*'[I say] I'm not here to tell you what to do, but whatever decision you make we'll work with you and this is all the other bits of support we can offer you'.*

#### 4.1.1.2.2.2.1.2 Research uncertainty

*'I discuss a number of things about medication in particular, including a sort of baseline risk of abnormalities, the uncertainty. I think it's very important to be honest with women about what we do know and what we don't know and really to go through a whole lot of different issues to help them think about how they might weigh up the risks and benefits in their own individual case'.*

Others agreed there was a need to contextualize the research data, but some found it difficult to address in the limited time available:

*'I always spend some time talking about baseline risks. There's very little time in an outpatient appointment that's the trouble, and I spend a significant amount of time trying to explain to people that if the world were perfect, there would still be a 2% - 4% risk that ...things might not be as they wish and that's a really important concept because otherwise, you can attribute everything to either illness or medication and we don't know that that's what it is most of the time.'*

#### 4.1.1.2.2.2.1.3 'Mention the unmentionable': raising difficult issues

The group talked about the extent to which professionals should raise difficult issues which women themselves might dread asking about.

*'Raising the idea that your illness, that is scary enough in itself, might be causing damage to the child, I think it's that that people find difficult to think about, so I think it is our job to raise it and to mention the unmentionable because then you can contain the*



*anxiety and ...direct people to a variety of places where they can find support.'*

The Health Visitor agreed:

*'I think it's an important conversation to have with women in terms of getting some honesty and ...giving permission for people to actually talk about those things ...it's really vital'.*

The other background anxiety often left unexpressed that some group members felt needed to be addressed was the fear of Social Services' involvement. An experienced perinatal psychiatrist recommended dealing with this issue in a forthright way:

*'I think that's very important ...to say that you think they need to be referred, why they're being referred and that referral doesn't mean I'm referring you because I think you shouldn't have care of a baby; you might want referral to do some kind of an assessment'.*

#### **4.1.1.2.2.2.1.4 Discrepancies with other sources of information**

This contained two sub-themes: *Correcting advice from other medical professionals* and *Internet surfing*.

##### **4.1.1.2.2.2.1.4.1 Correcting advice from other medical professionals**

The decision-making process was often further complicated by non-specialist health professionals giving advice which a specialist would not:

*'It can be tricky in that situation where the woman's been given some advice, mainly by a general psychiatrist, and they've looked up something like the Maudsley Guidelines and recommended an antipsychotic and we kind of say, well it's not quite as straightforward as that. But you don't want to raise lots of anxieties, so it's that balance of how you deal with information that's been given by various different professionals.'*

The group agreed that these problems would be lessened if all professionals received a good standard of perinatal mental health training, as the midwife acknowledged:

*'...people often go from the psychiatrist to the obstetrician, to the midwife, to the health visitor ...and I think what we really need to do is make sure we're all saying the same thing, because that's the danger - that us with little knowledge and you with a lot more knowledge ...in some areas - will give very different answers.'*

#### **4.1.1.2.2.1.4.2 Internet surfing**

Many women came to their appointments having surfed the internet and found information on bipolar and pregnancy which contradicted what they were told, confusing them and making them more anxious.

*'You do your best to allay anxiety and contain and do what you can, then they go home and ...google it, [and]...I try and say look, this is the type of evidence we try and collect; you know, you'll see different things when you look it up. But I'm not sure if that really is as protective from anxiety when you're actually sitting in front of a computer screen at home seeing those other numbers'.*

#### **4.1.1.2.2.1.5 Coping with volume of information**

It was identified that women and their partners often struggled to cope with the amount of detailed information given to them in a short, intense conversation. As one group member said:

*'I think that they get to the point where they obviously cannot appraise the information themselves accurately so they hear risk, or they hear something about some research and then the next minute they've imagined that their child is now permanently ...damaged and so I think it might be helpful to be honest about it, but raise it as something that you can reassure them about rather than freak them out.'*

Providing a written summary of the information and what had been discussed was viewed by all as a good idea:

*'I usually say I'm going to give you lots of different information. Some of the information is very complicated and so don't feel worried if you don't take it all in ...I always say I'm going to send this all to you in writing and you will have time to think about it, and you can come back to me with questions afterwards.'*

This psychiatrist said another thing that could help was to give them information about what support or services are available, particularly peer support *'or if we do detect that they're finding it difficult, what interventions or support can help modify or mediate their concerns.'*

A fellow psychiatrist agreed:

*'I often use the bipolar networks just to give people other examples of women who have been through the same thing to normalise it a bit and [offer] ...a bit of reassurance that this isn't just them and their families, it's happened to lots of other women as well.'*

#### 4.1.1.2.2.2.2 **Professional awareness of concerns peculiar to the perinatal context**

At several points in the discussion, group members expressed their own doubts and anxieties; this theme coalesced into three sub-themes: the extremely high stakes for mother, child and wider family and the additional problems caused by providing advice too late; the danger they perceived of unintentionally exacerbating a woman's anxiety, and the risk of focusing too much on the mental health issues and neglecting a woman's physical health.

#### 4.1.1.2.2.2.3 **High stakes: timing of advice**

A perinatal psychiatrist said it was particularly challenging when they were unable to have a conversation with a woman when she was still well, as if she became pregnant unexpectedly, stopped her medication abruptly and became very ill, it was then very difficult to keep mother and baby safe. She described how a patient of hers had been in this situation when pregnant:

*'She was angry with everybody and ...didn't want to take medication. With someone like that it's very hard to ...move forward in any way that you feel is going to be safe.'*

This doctor was concerned that not enough women were encouraged to plan for how bipolar would impact on their pregnancy and vice versa:

*'I think the worry sometimes is that we don't see women at that key point. By the time we see them they're already 12 weeks plus ...and they'd be on all sorts of medications and it hadn't really been discussed and then suddenly you have the situation to try and sort out after those first few months ...that can be quite tricky'.*

The group agreed that it wasn't just when women with BD were actively thinking about having a child that they should be receiving advice; it would be preferable to start these conversations much earlier. The psychiatrist who worked in adult psychiatry part of the time concurred:

*'Especially since a lot of the women we see don't plan their pregnancies. So that's another big issue for me as an adult psychiatrist, thinking about the behaviour of people who don't always know when they're going to get pregnant, so thinking about it for all women of childbearing age who have got a history of bipolar almost and affective disorder.'*

There was a general consensus that this would be preferable:

*'there's probably a stage before that [when a woman seeks preconception advice] that services need to consider, which is what discussion you have with all women in services about these issues, not letting it just be when the woman comes and tells us that she's pregnant or that she's going to try for a baby and I think that is something that less often happens, because everybody is so busy doing everything else.'*

#### **4.1.1.2.2.2.4      *Danger of exacerbating anxiety***

The question was posed that having detailed decision-making discussions, "particularly with regards to medication, and discussing all the potential evidence", might exacerbate a woman and/or her partner's anxiety about the pregnancy and postpartum period, and several members of the group agreed that they were concerned about this possibility.

*'Yes, I worry about that. I think there's so much research. I try and give some sort of general introduction to explain to people, on a very basic level, what kind of studies we'd want to have and the kind of studies we actually have got, and that if they go trawling on the internet they will find occasional reports of different things, but*

*what I'm going to tell them is the main things. ...but not every single detail of anything that's ever been found because I think that's hugely anxiety provoking. But I think there is a difficult balance to be had there.'*

Several group members concurred and a perinatal psychiatrist raised the additional point of the woman's state of mind and capacity to mentally digest the information:

*'There is such a dilemma because you are introducing a capacity for people to be anxious and the very vulnerability to a mood disorder means that people can have quite distorted cognitions about the impact of their own illness on the baby, and the requirement of them to take medication makes them feel guilty as well, so it all feeds into what is already going on and I just really struggle with the numbers'.*

#### 4.1.1.2.2.2.5 ***Danger of missing physical problems***

One perinatal psychiatrist was keen to highlight the danger of "diagnostic overshadowing" and stressed the need to ensure the physical wellbeing of the woman was not neglected because of the focus on her mental health.

*'...thinking about physical issues as well ...the bipolar disorder's a really important one to be planning for and that's why they're seeing me, but there may well be other things going on in terms of concerns about medication and metabolism and all those sorts of normal things that everybody's got to be thinking about, blood pressure and whatever else, difficult delivery, all sorts of things'.*

Another perinatal psychiatrist agreed:

*'I think something else is not to forget about all the normal anxieties that women have and that the focus can just be all on the mental health and all on the diagnosis and the medication and just to really explore the general worries that women might have in just the same way as any other woman.'*

#### 4.1.1.2.2.2.6 **Individualization**

The group concurred that it was very important to customize any advice to the individual needs of each woman. There were five main aspects to this: personal history; personal preferences regarding the amount and level of detail an individual might require and their perception of risk; cultural considerations and degree of partner involvement.

##### 4.1.1.2.2.2.6.1 *Importance of personal history*

A perinatal psychiatrist described her approach:

*'I think it's very important ... to help them think about how they might weigh up the risks and benefits in their own individual case and very much individualize it looking at their own history of illness and the medications that they've been on: what they've found helpful, what they haven't found helpful - think about risk of relapse.'*

Others agreed, with another perinatal psychiatrist advocating taking

*'a sort of holistic view of a woman. So what are her support structures? What actually happens when she gets ill with her bipolar illness? So what is the fallout of her not staying well?'*

Her colleague said that:

*'for some women the decision is easier than for others. For example, if you've had multiple episodes of illness and clearly relapsed quickly when you've come off medication then realistically you probably need to stay on it. For many who have had only one or two episodes it's much more tricky.'*

##### 4.1.1.2.2.2.6.2 *Personal information preferences*

This professional explained how the amount of detailed information a woman wanted before making a decision varied from person to person:

*'Some seem to have done lots of reading and want to clarify that the decision they've already made is a reasonable one. Some women seem very fixed about definitely wanting to continue*

*medication (because they're terrified of relapsing), or definitely not wanting to take medication (because they don't want to take any risk of harming the baby at all) and others are very unsure and really agonise about the decision.'*

It was important not to overload women with too much detail:

*'If you do pile on too many bits of information about every single risk, you can see that even with a Paracetamol packet, it can be overwhelming and women will not take anything because they're so frightened that whatever they do, they're going to do something terrible to their baby'.*

Her fellow perinatal psychiatrist agreed:

*'It's probably worth asking them how much information they want to know, because some want to know everything and others don't.'*

People also differ in their value judgements about levels of risk, as this perinatal psychiatrist explained:

*'I think we've all got different perceptions of risk, so some people are hugely relieved when you say the risk is probably less than 1% and some people say, well I'm not taking any risk at all with my baby'.*

Another group member explained her approach:

*'I say to people everyone will see this information differently, there's no right or wrong about it, you know some people will see one in 100 risk as a big relief because they were hugely worried that staying on the medication that they know has always worked for them would be a huge risk for their baby, so they see that very positively and other people will be very anxious about it'.*

#### 4.1.1.2.2.6.3 Cultural considerations

Some professionals highlighted the need to understand the wider social context.

*'In terms of decision making, understanding the family and the cultural pressures on the mother to have a baby ... I certainly think, particularly with women from different cultures, understanding the other influences on her pregnancy intention, the kind of decision-making processes, is also important.'*

#### 4.1.1.2.2.6.4 Degree of partner involvement

Where the woman had a partner, several group members highlighted the importance of involving him or her in the decision-making process, especially regarding medication, about which "partners sometimes have very polarized views".

*'I try to encourage the partner to come too, it doesn't always happen because I find sometimes the partners have not been around before when the woman's been ill and they may have unrealistic expectations, or no knowledge at all and the woman is doing this by herself, so I really like both to buy in to whatever we're talking about'.*

This was best done right from the beginning or it could cause difficulties later, as one member illustrated:

*'I recently had a woman whose partner was very into herbal medicine and he came with all this information and I was trying to explain about evidence and that yes, it may well be good, all this stuff, but there are no studies.'*

Another member concurred: 'the number of people I've seen who look like they've taken it on a bit you know, you do your best to allay anxiety ...then they go home and partner, mother, sister goes, "she said what?" – you know - "why would you be taking medication like that?"



#### 4.1.1.2.2.2.7 **Advance Planning**

This contained four sub-themes: *Need for specialist advice; Co-ordination between services; Having a detailed plan in place, and the obstetric pathway.*

##### 4.1.1.2.2.2.7.1 *Need for specialist advice from a perinatal psychiatrist*

All recognized the “complexity” and “challenges” of making these decisions and that it needed someone with specialist knowledge to give advice.

*‘It’s sometimes very scary, because often when people get pregnant out of the blue and they see their CPN or whoever it is and say ‘I’m pregnant, I’m not going to take my medication’ [it needs] someone to step in at that point ...and say well hang on a minute, it would be good to find someone who you could have a talk to about all of this.’*

The Community psychiatric nurse who was perinatal lead for her area (which did not have a full perinatal service) said this caused real problems:

*‘It is difficult to get all the professionals in the room who would need to be involved to fully make the decisions ...For example one of my patients was on lithium and really wanted to breastfeed, she needed to know how her baby would be monitored in order to make this decision which is something we had to find out from the paediatrician. Knowing that baby would need to have blood monitoring and stay in hospital longer enabled her to decide not to breastfeed but to remain on lithium as her risk of bipolar relapse was so high.’*

##### 4.1.1.2.2.2.7.2 *Co-ordination between services*

The need for a high level of communication between different agencies was highlighted, as the Health Visitor pointed out:

*‘What’s really important for us is sharing that information and talking about risk and relapse signatures. Very often with health visiting there’s a lack of that information that comes through, the services are very separate and so the health ...might not pick up on the early signs, but if there was a shared plan, an integrated plan, through from psychiatry, community mental health teams, midwives, through to health visiting then that would enable us to*

*really pick things up very, very early. It would also enable us to have a plan of what that woman would want to happen, where her children would go and, you know, which services would be involved and which members of the family would be supporting her.'*

The midwife in the group agreed that it was essential for psychiatric professionals to liaise closely with other maternity staff:

*'I think that's really important because I think there's probably a fear amongst some midwives and obstetricians about mental health because they don't understand it in the same way as they do pregnancy health, so I think to have that close liaison between the midwife, the obstetrician and the mental health team is so vital for any women who have bipolar disorder, or any other serious mental illness, because often the woman ...falls into the trap of being led by an obstetric team and she misses out then on the social midwifery care.'*

This part of the discussion underlined the postcode lottery that exists in the UK with regard to perinatal mental health services, as the level of service called for above was already being provided in other parts of the country, as this psychiatrist explained:

*'In the team that I work in, for all the bipolar women we'd have a meeting when someone's about 30 or 32 weeks, with the woman, any family members, partners, whoever else she wants to bring and all of the different professionals, including the health visitor and all of these different issues would be discussed, not just medication but the support, the risk of relapse, relapse indicators, the plan, what will happen when she comes into hospital, what will happen when she goes home and that's the point of information sharing and then all of that gets written down and everyone has a copy and then it's very, very clear and my experience of feedback from women is that then they know that everybody knows and they don't have to go through it again at the point of delivery and that, I ...think, is helpful.'*

Another group member commented: *'that's great in your area ...and ...in some other areas there's promising practice, [but] in other areas it's a disaster'.*

The community psychiatric nurse emphasized that social factors needed to be taken account of:

*'For example we use [an] MBU ...which is more than an hour's drive away so potentially difficult for patients to remain in close contact with their partner and other children, or sometimes patients have had terrible hospital experiences and want to avoid admission at all costs which plays a role in how great a risk of relapse they can take.'*

#### 4.1.1.2.2.7.3 Detailed Plan

It was agreed that one way to facilitate good co-ordination between different professional groups was to have an easily accessible, detailed care plan. It was suggested that such a plan be put in place as early as possible:

*'I think the earlier you start that conversation the more you give women a chance to think about and involve other people [so that] ...if a relative comes over from a different country, or someone decides to move in with them, all those things can be set up, whereas if you start it too late it gets too difficult to organize.'*

The CPN stressed the importance of planning for a woman's other children and giving her autonomy to decide in advance how she wants to be treated if she should become unwell:

*'I would talk to people about what happens if they are ill and I make a very detailed plan about that. What do they want to happen and who will look after their other children and where do they want to go? So they can have as much involvement in a plan, if they do become unwell, as possible and make as many decisions while they are in a good position.'*

Any such plan needed to include issues such as sleep and breastfeeding.

*'A really key thing in my experience is sleep and not having sleep for those first couple of nights and the women tend to have to stay in hospital, even if they don't want to, because they've been on medication so their baby needs monitoring and so sometimes, just giving them some light sedation and looking after the baby overnight in the nursery can make such a difference ...Or letting*

*them have a private room and their partner stays over and does the baby care.'*

There was some disagreement about breastfeeding, with the midwife stating 'they should be supported to breastfeed', and others adopting a more flexible approach, as this psychiatrist expressed:

*'I think they should be supported to do what they want, because I think people feel very guilty sometimes if ...for whatever reason they've decided that they don't want to breastfeed ...sometimes they feel very pressured that they should be breastfeeding.'*

#### **4.1.1.2.2.2.7.4    Obstetric pathway**

The midwife in the group, who was working in an area with only a limited perinatal service, thought women with BD should be warned that they would not be offered the less 'medicalised' maternity pathway.

*'I think women need to know that they are likely to be on an obstetric pathway as opposed to a midwifery led pathway when they have bipolar disorder or serious mental illness and whether that's right or not I'm not going to debate but it is very likely that that's where they will be so they need to have that information about what that pathway involves and the fact they are going to be on a hi-tec delivery suite and sometimes that's going to restrict their choices around their mode of childbirth, and I think that's a really important thing to know, because when she then enters that pathway, the chances are you're going to have more intervention as most delivery research studies have shown that, and the intervention itself could actually predispose that woman to becoming ill again, because it increases her stress levels etc.'*

A perinatal psychiatrist from a well-resourced area said women in her hospital would have more choice:

*'We're very flexible and if women want to go onto the 'Home from Home' delivery unit, unless they're on something like lithium where we're obviously going to have to really monitor that. We've also got a team of midwives that works very closely with our team so we really try and help women to have the kind of delivery that they want ...as far as we possibly can.'*

## **4.1.2 General Adult Psychiatrists**

As illustrated by the data from Chapter 3, most women with BD in the UK who are seeking advice on pregnancy and childbirth see a general adult psychiatrist rather than a perinatal specialist, so I considered it important to hear the experience and views of this group of professionals.

### **4.1.2.1 Methods**

#### **4.1.2.1.1 Design**

Following difficulties recruiting general adult psychiatrists to focus groups, it was decided to conduct interviews, chiefly by telephone. Thematic data analysis based on grounded theory (as employed in the two previous arms of the study) was then conducted.

#### **4.1.2.1.2 Ethical Approval**

This study received ethical approval from the Psychiatry, Nursing and Midwifery Research Ethics Panel of King's College London (Ref: LRU-16-17-3755).

#### **4.1.2.1.3 Recruitment strategy**

This was an opportunity sample recruited via professional networks. Inclusion criteria was general adult psychiatrists working in UK.

Potential participants were approached by email with an information sheet attached (see Appendix 10) to ask if they were willing to consider participating. There was no pressure to participate as they could ignore the request if they chose. If they agreed, they were asked to sign a consent form (see Appendix 11) and a date and time for the interview was arranged. Participants were given the opportunity to request sight of

their quotes before use.

#### **4.1.2.1.4 Development of topic guide**

A topic guide was developed based on the themes that had arisen from the qualitative study conducted with women reported in the previous chapter and in collaboration with my supervisors who are both perinatal psychiatrists (Figure 4.1 above).

#### **4.1.2.1.5 Setting and procedure**

Interviews lasting 20-50 minutes were conducted by telephone (11) or in a private room at the IOPPN, King's College, Denmark Hill, London (3) in the period January to March 2017. Some information on socio-demographic characteristics, employment and professional training was recorded and the topic guide was used to prompt participants to express their views.

#### **4.1.2.1.6 Data management**

Interviews were audio-taped and transcribed verbatim by an independent transcription service approved by the IOPPN. All data were stored securely on a university computer, no verbatim quotes were used in any publications which could lead to identification of the participant, and all quotes were anonymised.

#### **4.1.2.1.7 Analysis**

The transcript was read several times and an initial coding frame developed to aid thematic analysis (conducted as already described in chapter 3). To enhance reliability and guard against subjectivity in the interpretation and coding of data, another qualitative researcher, Dr. Emmeline Lagunes Cordoba, independently coded a proportion of the interview transcripts before meeting to compare results and resolve differences. After achieving a 90% inter-rater agreement the results were discussed with my supervisor (LH) to achieve consensus.

#### **4.1.2.2 Results**

##### **4.1.2.2.1 Participants**

Out of 22 psychiatrists approached, 14 agreed to take part. Eight were currently working in London, with six based outside the capital including rural Somerset and Fife. Eight were male and six female, with an average age of 35.3 years (30 – 46). Twelve were white British, 2 Asian British. Their experience as psychiatrists varied from 2 to 15 years (average 6), and they worked in a variety of settings: inpatient, urban and rural community teams, a psychosis team, woman's PICU (Psychiatric Intensive Care Unit), general adult liaison and assertive outreach.

##### **4.1.2.2.2 Themes**

Analysis of the interviews with general adult psychiatrists generated three overarching themes in relation to their interactions with women with BD about pregnancy: *Timing*, *Communication* and *Views on Future Practice*. *Timing* encompassed: the optimum time to discuss the issue; fear of engendering anxiety, unplanned pregnancy, time constraints, mental capacity and prescribing challenges. *Communication* coalesced into two major headings: Clinical Confidence and Barriers to Shared Decision Making. The former included psychiatrists' concerns over their own research knowledge, the need to treat each patient individually and the challenge of achieving a balance between adequately informing women without frightening them or diminishing hope. Barriers identified were: stigma, fear of Social Services, lack of care continuity and the challenges of comorbidity. The themes, sub-themes and illustrative quotes are shown in Table 4.2.

***Table 4-2: Themes from general psychiatrists' interviews***

Timing	Communication		View on future practice
Optimum time to discuss BD pregnancy issues	Clinical confidence	Barriers to SDM	Specialist referral
Time constraints	Research knowledge	Stigma	Information Resources + Support Resources
Unplanned pregnancy	Individualization	Fear of Social Services	Improved training or more specialist services, including service reconfiguration
Fear of engendering fear	Achieving a balance <i>1) Avoiding anxiety</i> <i>2) Puncturing hope</i>	Lack of care continuity	
Capacity		Comorbidity + complex needs	
Prescribing challenges			

#### **4.1.2.2.1 Timing**

When is the best time to discuss the risks of pregnancy with women diagnosed with BD? When asked whether such discussions were a routine part of their consultations with women with BD of childbearing age in their care, there was a disparate range of reactions. Most said that pregnancy wasn't given the priority it should be. Some said they didn't normally discuss pregnancy risks with a newly diagnosed woman:



*'I don't think that's something which would be within my routine...that's lower down the list of priorities' (P5).*

Participant 11 agreed:

*'Frankly it's not a priority, there are so many things we have to fit in to the short time we have ...it's not something I would ever think to talk about, I have to say'.*

Others, particularly those operating in acute settings, said that it was not always appropriate to talk about it on first meeting as:

*'in that first episode ...where somebody is manic and they're sectioned and they're in hospital and you're starting them on treatment for the first time, then I think we are ...very focused on the short term and the conversation about longer term and pregnancy probably gets delayed' (P6).*

#### 4.1.2.2.2.1.1 **Time constraints**

The time allowed for consultations, especially when a woman had just received a diagnosis and had many questions about the disorder and its likely impact on her life, was not considered sufficient to discuss everything thoroughly.

*'With the time constraints – to have a long, detailed conversation about something that doesn't appear to be immediately relevant at that time ... can be quite difficult.' (P7)*

Participant 9 agreed that, especially on an acute ward, they didn't always cover pregnancy:

*"It's something that we will try to cover with any women of childbearing age, I mean that was always our aim but I can't say we always did that. I think sometimes those things did get missed'.*

Notably, those interviewees who said they did not routinely raise the issue with their female patients with BD were all male. The six female psychiatrists in this sample appeared to rate it as a higher priority, even those working with the most acutely ill in-patients. For example, participant 1, who worked on a Psychiatric Intensive Care Unit

or PICU, said it was “routine” to discuss child bearing plans, contraception and issues of medication with women. Another interviewee who also worked with patients recovering from psychotic episodes, concurred that such discussions were “part of my routine checklist with everybody I talk to who is female of childbearing age with bipolar” (P10). This (female) psychiatrist said it was “absolutely” a priority when seeing a newly-diagnosed young woman with BD:

*‘It’s sort of the first thing that ...I am aware of when I see a woman is that she can have a baby ...that’s the first thing that you start thinking about.’ (P10)*

#### 4.1.2.2.2.1.2 ***Fear of engendering fear***

Some said they didn’t want to “frighten” a woman so much that she felt compelled to stop taking her medication, or that her ‘capacity’ to take the issues on board was in doubt (discussed below 4.1.2.2.2.1.4).

*‘I think the biggest challenge, to be honest with you is the timing of when we do that. If you’re seeing someone who’s 23 or younger, making the initial diagnosis ...it can seem quite strange. You don’t want to terrify them’ (P7).*

However, in considering this issue more, this participant concluded that it would be better to routinely discuss the matter early on, because otherwise

*“you fall into the trap of if that doesn’t happen at the beginning it generally then doesn’t happen at all”, they end up being discharged and “the next thing we know is a referral back [because] she’s pregnant, and ...you’ve missed giving her the opportunity to think about it beforehand” (P7).*

#### 4.1.2.2.2.1.3 ***Unplanned pregnancy***

For this population vulnerable to the recklessness and hypersexuality often associated with a manic episode, unplanned pregnancy is a significant risk and many interviewees reported most of their experience of talking to women with BD about childbirth had taken place after their patients had become pregnant accidentally. As participant 13 said:

*"I can only remember one planned pregnancy to be honest: they come to me post-conception".*

Others agreed there was a need to raise the issues earlier and emphasise the need to plan for pregnancy:

*'I think it probably does happen quite late and sometimes it is that they're already pregnant and then we're probably talking to them about risks and we probably should have been thinking about it earlier on' (P7).*

*'My experience has been that people say that they're not thinking of getting pregnant or not now and then a pregnancy might be unplanned... Given how many pregnancies are unplanned, I do think that psychiatrists in general need to know much more about pregnancy and mental health problems' (P6).*

#### 4.1.2.2.1.4 **Capacity**

Even for those who prioritized pregnancy discussions, these were often difficult to have with acutely ill women, such as in the PICU.

*'[We discuss it routinely but] that having been said, because of the context where I work it is the case that the vast majority of patients do not have capacity at the time of the initiation of the treatment plan to consent to decisions around their medication. We would talk to them, and we keep talking to them on multiple occasions, but their ability to take any of that in, retain it, and weigh things up will fluctuate. But it is something that we continue to advise on.' (P1)*

*'The memorable issue would be around insight and whether or not they actually believe that they suffer with bipolar disorder or that they're at risk of relapse during pregnancy' (P13).*

A consultant in charge of an inner-city outreach team and high dependency unit (P3) said the majority of his patients were under section and "therefore not in a position to make those decisions", but he "usually" tried to have ongoing discussions about pregnancy risks if they were of childbearing age.

#### 4.1.2.2.2.1.5 **Prescribing challenges**

When discussing timing of pregnancy discussions, many general psychiatrists referred to the need to avoid using Valproate with women of childbearing age (as strongly recommended in the NICE guidelines because of the teratogenic risks associated with it (2014)). Indeed two used the same phrase to say that they had had it “drummed into them” not to use it if at all avoidable. However, some psychiatrists found this edict difficult to adhere to because when a patient’s illness was very severe the short-term gain was worth the teratogenic risk:

*‘There’s only a couple of times that I can think of when I’ve started a woman of childbearing age on Valproate, usually when she’s got an illness that’s really difficult to control and other things haven’t worked.’ (P7)*

In such a situation, this participant said he would strongly advise his patient to take reliable contraceptive measures and tell her if she were to think about becoming pregnant they would “ideally wean her off it and probably put her back on an antipsychotic” beforehand.

Those working in acute settings found the policy even more challenging:

*‘In the intensive care unit, one of the problems is that you’ve really, really, really unwell women and we’re prescribing Sodium Valproate pretty regularly because there’s no getting around it, they need it, because they’re so acutely unwell. And you ...inform them about the risks of teratogenicity, but you’re also in sort of a tricky situation because you need them to take this medication and they do not in that environment, pretty much normally by definition, have the capacity to make decisions about their medication. I will say, “Look we need this at the minute, you are really poorly, we are not probably going to keep you on this long term, you know if you’re thinking about having children...”’*

The psychiatrist quoted made the point that a degree of experience dealing with such issues was needed to balance the risk of relapse with the risk of an unplanned pregnancy while taking Valproate.

*“I had a real problem not long ago ...when a very well-meaning junior doctor switched [a woman] from Valproate to Lamotrigine on*

*the grounds of NICE guidance without any consideration of that person's risk formulation ...this was someone who was profoundly unstable and really risky ...and sure enough, I see her four months later so bloody unwell because she can't cope on Lamotrigine. There's something very important about the seniority of review for these women" (P10).*

#### **4.1.2.2.2.2 Communication**

The second overarching theme of Communication included two first order themes:

*Clinical Confidence*: whether general psychiatrists felt equipped to advise women with BD about pregnancy and how this affected their communication about decision-making (encompassing Knowledge of research, Individuality and Achieving a balance); and *Barriers to shared decision making* (Stigma, Fear of Social Services and Lack of care continuity). See Table 4.2.

##### **4.1.2.2.2.2.1 Clinical Confidence**

Many interviewees admitted they lacked confidence advising on the various risk profiles of medications in pregnancy because the evidence "seems to change so rapidly" (P14) and/or they had had little experience of discussing pregnancy issues with women with BD.

##### **4.1.2.2.2.2.2 Research knowledge**

As participant 1 admitted:

*'the honest answer is I don't have particularly contemporary information at my fingertips. ...I sort of have a hazy understanding that Valproate's really bad, Lithium's not much better, Carbamazepine is probably the safest ...[incorrect]... that antipsychotics might not be so bad and that probably you'd use them in preference, but all of that needs to be weighed against the massive risks of manic relapse during pregnancy and in the aftermath of the birth'.*

The situation caused "anxiety" in general psychiatrists, according to participant 9:

*'I think people worry that the information they thought they knew changes quite quickly and [they] don't want to be the person who prescribes the medication that causes a problem either in breastfeeding or pregnancy'.*

#### 4.1.2.2.2.3 **Individualization**

One psychiatrist who worked on an acute woman's ward in southern England said she usually saw women with BD when they were already pregnant.

*'I find it difficult because often people want to know very specifically what's the likelihood of this happening and that happening and of course you can't really tell for individual women, so it's sometimes difficult to convey the degree of uncertainty around the risks of taking or not taking medication and so on. (P9)*

A young psychiatrist working in a rural setting agreed:

*'It's really important to be honest with people ...you can quote figures but obviously applying that to an individual is incredibly difficult and to actually interpret that in the context of that person's illness and how they've coped with symptoms' (P7).*

#### 4.1.2.2.2.4 **Achieving a balance**

Psychiatrists were concerned about being able to convey the seriousness of the risks to women without a) frightening them or b) diminishing their hopes for the future and so adversely affecting their recovery.

##### 4.1.2.2.2.4.1 **Importance of not scaring women**

*'I think it's very important to be upfront with patients about how high risk it is, but whether or not I do, I don't know. There's a balance to be struck between wanting people to have all the information but not scare them away from services" (P9).*

Participant 5 agreed:

*'There's a lot to take in. There's a balance between giving a diagnosis and really hammering home the gravity because*

*obviously bipolar disorder is a serious and chronic illness, [with] implications perinatally but also in terms of heritability...and it's hard to really make predictions because ...everyone's different'.*

#### 4.1.2.2.2.4.2 Danger of puncturing hope

Interviewees mentioned more than once that the responsibility they felt to communicate the risks of pregnancy for a woman with BD was sometimes compromised by a reluctance to be “negative” about a newly-diagnosed patient’s future. As participant 9 said:

*‘Some people I’ve worked with ...just want to say “Right okay, this is your diagnosis, take the medication, things will be fine” ...underplaying it a bit. Not with any malice but just not wanting to kind of ...scare them off too much, you know’.*

Regarding this reluctance to detail the risks of pregnancy for women with BD, participant 1 said she “had theories about why [psychiatrists] don’t talk about it”.

*‘I think that when someone has a first manic episode there is a certain movement in the early intervention services that emphasizes the instilling of hope and sometimes that is at the expense of informing the patient fully about what’s actually happened.’*

She went on to relate the story of a colleague who, at the discharge meeting, had informed a patient who had had a manic episode of the consequences of Valproate and the possibility of relapse. After the meeting, he was “chastised by the psychologist for being negative”. She said she thought that was “a big issue” as he felt he “had to discharge his duty” but having a manic episode was obviously a devastating thing to happen to someone and she could understand a clinician not wanting to scare their patient so much that they “enter an avoidant cycle and want to block it all out”. Nevertheless, she thought it was “a scandal” if psychiatrists omitted to talk about pregnancy risks at an early opportunity:

*‘I think a woman’s right to control her fertility and a woman having knowledge about teratogenicity and about the possible consequences to her mental health of pregnancy and childbirth, is absolutely essential.’*

#### 4.1.2.2.2.5 **Barriers to satisfactory shared decision-making**

Several impediments to helping women with BD and their partners make decisions about pregnancy have been touched upon already, but psychiatrists cited three barriers in particular which sometimes made having these delicate conversations more difficult still: Stigma, Fear of Social Services and Lack of care continuity.

#### 4.1.2.2.2.6 **Stigma**

Interviewees were conscious of women anticipating that they would encounter stigma and discrimination against them becoming mothers.

*'What women find difficult is when they feel that the attitude from their mental health provider is "You shouldn't be having children. You can't... I'm not prepared to discuss this with you," that you're being somehow irresponsible if you want that. What I want with my patients is to know that you see them as a whole person not just their mental illness, and if they want to have a family then they can but there is extra support there we'd really like to give and that it's not ever a kind of dictating thing. I think you can do it very easily in a human way, not in a stigmatising way.'* (P2)

As this quote demonstrates, the psychiatrists in this sample did not exhibit the stigmatizing attitudes often complained of by the women interviewed in Chapter 3. But the fact that women themselves anticipated they might be stigmatized could contribute to having a less open and frank conversation.

As participant 9 said:

*'I've met quite a few people who think that just because they have a diagnosis people are going to perceive that they shouldn't be having children. I think that's a worrying thing too – whether they're less likely to be honest about things and so on'.*

#### 4.1.2.2.2.7 **Fear of Social Services**

For some women, this anxiety over being stigmatized as a bad mother also fed into a fear that, if they gave birth, their child would be taken away from them:



*'I think from the women themselves often there's a real fear about "Will I be able to keep the baby" (P9).*

Participant 1 saw this fear as a significant barrier to frank discussion:

*'I think people are terrified of social services, I have to say that being a doctor and trying to be reassuring about social services is completely ineffective ... People actually walk out if you mention social services, [they] walk out if you mention "I need to fill in this child risk screen ... so it is a really sensitive issue.'*

Another interviewee said that, compared to schizophrenia, bipolar disorder was far less stigmatized by clinicians and society generally so

*"I don't experience that as a barrier but I experience it as a complexity when starting to do their planning and I have to say "We'll need to make sure you've got additional support ... and that might involve social services" (P10).*

The consultant who cared for very high risk women in an inner city outreach team (P9) made the point that for some of those women who were using substances, poorly engaged with services and often in abusive relationships, "the chances of them keeping a child" were low. He said he felt he had a responsibility to tell them that, and that family services would be involved from the beginning.

#### **4.1.2.2.2.8      *Lack of continuity of care***

Interviewees highlighted the difficulty of not being able to develop a rapport with a patient before having these finely balanced conversations and feeling confident to share making such momentous decisions together.

*'I just feel that the pressure is that the moment someone is out of an acute episode they get discharged straight back to their GP and [if they have another episode] the GP then refers them back to you. It's shocking. And in terms of building up that trust and rapport if you only see your psychiatrist when you're in extremis, how do you get a view that this is somebody who knows you and you can trust to recommend things?' (P2)*

The complex risk/benefit analysis involved in bipolar pregnancy decision making was viewed by many as particularly requiring the development of a meaningful therapeutic relationship.

*'I think there's a lot to take in. That's where a long-term relationship with a patient really comes into its own and a skilled psychiatrist that understands the disorder and understands the person and has a longer-term relationship - that's such a benefit, and, as we know, that kind of thing is rarer where our interactions with patients are less long term. (P5)*

#### 4.1.2.2.2.9 **Comorbidity and complex needs**

Another barrier to effectively implementing shared decision making which was emphasized by several clinicians working in urban areas, and especially in acute settings, was the problem of communicating with women who sometimes had multiple comorbidities and lived very dysfunctional lives.

*'We have a number of women on our caseload who have diagnoses of bipolar affective disorder and schizoaffective disorder ... most of them have fairly significant risk histories, either risk to their health and safety or towards others, some with very significant forensic histories and many have co-morbid issues alongside their mental disorder, particularly substance misuse disorders and personality disorders.'* (P3)

A woman in this situation might think about having a child when she wasn't well or stable enough to care for it and, according to three of the interviewees, they were very loath to tell her anything that might cause her to stop taking her medication at that point and so spiral downwards, as participant 10 explained:

*'The main barrier is when you've got someone who's actually still quite unstable, they may be still using drugs, they've got a chaotic lifestyle and they're on something like Lithium or Sodium Valproate and you're desperately trying to get them to stay on it - that can be a real problem because if you open up the pregnancy discussion you are going right down the route of well, actually these meds are really bad for you. And it's very difficult cognitively for some of these individuals but also emotionally for them to take on board what's a very mixed message of "I believe in hope and that you could be able to have children," and also the contradiction of*

*“You’re not bloody changing the meds at the moment because you’re far too unstable to do that.”*

A psychiatrist working in a high dependency setting said individual advice on decision making was often further complicated by social problems and traumatic histories.

*‘With the population we see here ...there is a high relationship between the bipolar illness and experience of trauma as well. So we’ve got the complexity of say seven out of nine patients in the PICU having experienced sexual abuse of some sort, and so the concept of pregnancy is complicated.’ (P10)*

#### **4.1.2.2.2.3 Views on future practice**

The third group of themes emerged from the views of general psychiatrists on how they thought the system was working in their locality at present (including their ability to refer to a specialist service), and what information and support resources – if any – they were aware of that patients could be signposted to. Discussing how things might be improved with limited financial resources, interviewees were asked whether they thought the best way forward was to extend access to specialist perinatal teams or to concentrate on improving the training in perinatal mental health of general adult psychiatrists.

##### **4.1.2.2.2.3.1 Specialist referral**

Psychiatrists working in rural settings and where there was no dedicated specialist service said they would manage women with BD in the community, liaising with the obstetric team, as this doctor in Eastern Scotland explained: *“We are quite good about talking to people ...and highlighting to them the need for increased monitoring and the risk of puerperal psychosis”* (P7). He added that he could also access an MBU near Edinburgh if needed.

A community psychiatrist in Somerset said his area had similar arrangements for women with BD, which he regarded as less than ideal:

*‘We have no ...service at all so they’re often care coordinated by the Community Mental Health Team, again who have no particular*

*specialist skills with managing people with bipolar disorder and pregnancy. There's a mother and baby unit up in Bristol which is historically really difficult for us to access so I tend to make contact with Winchester [MBU] and they seem ...happy to provide advice.'*  
(P13)

Other general psychiatrists with no local specialist team said they also might telephone a service in another area for advice, while some of those with a dedicated local team said they would automatically contact the specialists if a patient was planning a pregnancy or was already pregnant. But procedures appeared to be far from uniform: one acute ward psychiatrist in London said he thought the local specialist team “*would have more urgent matters to deal with*” than giving preconception advice (P11), and others spoke of the problems accessing such services in densely populated regions:

*'It really is too thinly spread and too inaccessible. There is clearly a need to have more, certainly in the south west. And that's highlighted more the few times when I've needed to access specialist services and it's been really difficult. They've either been completely full in terms of the inpatient units, or just unavailable (for advice) because they're busy ...so there's clearly a need for more than there are' (P13).*

#### **4.1.2.2.2.3.2 Other information and support resources**

When asked whether they offered patients any information resources, responses ranged from a lack of awareness that any existed to lengthy, detailed lists of resources to which women and partners could be signposted. Two interviewees said they used the Maudsley Guidelines; another their medicines information pharmacist; some used their own Trust leaflets on different medications; several said they would print out leaflets from the Royal College of Psychiatrists' website. Participant 1 said she used the “BDRN coping with your baby with depression leaflet (Bipolar Disorders Research Network); RCOG and RCPsych info sheets ...those are the resources I think are good”. The ‘Bumps’ website (information on medications in pregnancy) was also mentioned by two interviewees (P2, P7). Most of those referred to are specifically about individual medications which might be prescribed:

*'We've got Trust ...leaflets that we've signposted – those were mainly to do with medication, but I don't really know in terms of information about risks and so on about getting pregnant, no' (P9).*

When asked about any support resources for women and their partners grappling with the decision-making process, most general psychiatrists said they didn't know of any.

*'That's a good question. ...I know with bipolar there's a particular patient group but I can't remember the name of it – that might have some information. I would have to look into that ...' (P4).*

*Participant 3 said she "imagined there would be sections on all the usual mental health websites that they could look at regarding pregnancy, RCP, Rethink, Mind – all that stuff".*

Participant 7 said he *"couldn't think of anything in terms of actually supporting making the decision, and I suppose we would like to think and hope that we try to do that".*

Participant 10 agreed that the mental health team saw that as their role:

*'That's where the CPNs and the nurses come into their own. It's very rare I'm seeing someone who's not on care coordination, so my role is counselling, the medical, the sort of more holistic view of thinking about managing your illness, and then I find the nurses are more involved in the "This is what we're going to link you into".'*

#### 4.1.2.2.2.3.3 **Improved training or extended specialist services**

Considering the difficulties some women with BD encounter when trying to access information and advice on pregnancy decision making, interviewees were asked whether this problem would best be solved by providing better PMH training for general psychiatrists, or by extending provision of specialist services to cover the whole country. Opinions were divided: some thought they had received “adequate” or “pretty good” training, others thought it “pretty superficial”. Two psychiatrists over 40 years of age said they couldn’t remember having had any – and it was not compulsory as part of Continuous Professional Development. *“I guess you’d only probably do [a CPD event on perinatal mental health] if you had a particular interest in it”,* said one (P13).

On the question of putting resources into more specialist services rather than “upskilling” general psychiatrists, the majority (9 out of 14) said they would prefer to receive better training in the subject themselves.

*‘I suppose in an ideal world you could argue that specialist services do things better. In fact my personal view is the more that you – as a generalist - consider that this is specialist, this is not my responsibility - I don’t particularly like that approach. I think it is my responsibility. If I’m dealing with someone, particularly at an early stage, and I’m going to be making this diagnosis I think I should be aware of the issues and medication in pregnancy and the effect of the illness in pregnancy. ...I don’t think I can abdicate that by saying “Oh, there’s a specialist service that will deal with it.” (P7)*

Others agreed:

*‘I think there’s a huge gap in training there, and particularly around supporting mums with known mental health problems and linking up with social services and perinatal services. I think understanding the mechanisms of how that all works would be really helpful and basically, you learn as you get a patient and are asked to do things with such huge consequences for their lives. So, yes, I have a sense of unease with that.’(P1)*

*‘Referring where necessary for complex cases is important, but I think it’s sort of quite disempowering and not joined up if certain problems we just refer to another group because we don’t really*

*understand why or what the intricacies are. So I think we should have more basic training and manage patients more ourselves and refer where necessary. One of the issues here locally is probably a de-skilling around PMH because there is a specialist service.’ (P5)*

Those who disagreed, did so on practical and economic grounds:

*‘Having every single psychiatrist having detailed knowledge of managing BD in pregnancy ...won’t be achievable given that arguably you would then need to invest ...as much in every other condition and particular circumstances for it to be equitable’ (P13).*

*‘I would upskill ...because financially it’s just not viable. If we super specialize everything we can’t afford basic community services. Also it’s a risk of specialization across the board that you sort of regress to the mean.’ (P10)*

*‘From the conference I went to, specialist mental health services are meant to be a more cost-effective way of doing things’ (P9)*

#### 4.1.2.2.2.3.4 **Service reconfiguration**

Some thought the approaches could be combined: extend specialist services while also improving perinatal training for general psychiatrists.

*‘I think probably [my preference is] for generally psychiatrists to be trained because I think the perinatal services are really valuable and necessary for people who are at high risk during their pregnancy so I wouldn’t want everything to go to general psychiatrists, but I don’t think the perinatal service can see everyone with every mental health problem and not even everyone with bipolar disorder.’ (P6)*

Recent changes in how psychiatric care is delivered were also highlighted as a complication: secondary services see fewer ‘well’ women now who might be considering pregnancy.

*‘With service requirements these days, it’s very rare I see someone who’s well, because at that point they’re back in general practice ... they’re going back to the GP a lot quicker’ (P10).*

Participant 2 bemoaned this development, but added:

*'Maybe considering that it's moving into that model of just acute care, it makes more sense for the woman to go directly from the GP to perinatal rather than the middle man, if the middle man is the kind of community general psychiatrist she really doesn't know'.(P2)*

#### **4.1.3 Discussion**

Though the themes for the two categories of health professionals included in this thesis do not correspond exactly, reflecting not only their different experiences but also the different format of the two studies (focus group and individual interviews), there is also a great deal of overlap. Both groups cited Fear, Stigma and the challenge of communicating risk calculations as prominent components of their interactions with women with BD regarding pregnancy. Broadly speaking, both groups recognised the need for individualisation, the importance of social support and the danger of exacerbating anxiety and encouraging medication non-adherence. They were also in agreement that this was a difficult subject to communicate, particularly for the general psychiatrists who were less experienced in this area and were largely seeing a very different group: not well and discharged from secondary services like those referred to perinatal specialists for preconception advice, but still seriously ill enough to be in secondary care and often not capacitous. Those working in non-urban settings occasionally saw women who had been referred from their GP after a request for pregnancy advice, but this was exceptional in this sample. Both groups recognised the need for more training and called for better co-ordination between services to support women at this critical time.

The latter two findings were also reported by service users, who similarly believed that improved inter-agency collaboration and access to specialist service provision were necessary (3.3.2.5.4.3). A detailed analysis and discussion of how the professionals' themes compared to each other and to those in the study involving women with BD (Chapter 3) is presented in Chapter 5.



#### **4.1.3.1 Reflexivity**

As a qualitative researcher, I must acknowledge the possible influence of my own perspective on interpreting the data from health professionals and reflect upon the fact that I received poor treatment from my own local health service, in particular from a general psychiatrist from whom I sought pregnancy and postnatal advice. In retrospect I realise they were in a very difficult position as so very little research had been done at that time (1988-1990) to inform their advice, but I think it's important to acknowledge this experience in case it could be viewed as having coloured my analysis of the data. I have been careful to reflect upon this possibility in my notes and have endeavoured to remain neutral. Also, 'analyst triangulation' was employed, as described in Chapter 3 (Tuckett, 2005).

Nor was I considering sufficiently the whole spectrum of severity and complexity that a diagnosis of bipolar encompasses. The interviews with general psychiatrists, particularly those working in acute settings in urban centres, proved very illuminating in this regard. Many of the women with BD whom they see have multiple issues to deal with: medical, psychological, social and economic. Their lives have often been scarred not only by their mental illness but by childhood abuse and trauma, domestic violence, poverty, unemployment and social exclusion (Khalifeh et al., 2015b, Anderson et al., 2016). It is perhaps understandable that discussing plans to get pregnant are not prioritized by general psychiatrists who are trying very hard to keep them well. It is also necessary to reflect on the way in which my status as a service user researcher might have impacted on the responses of general psychiatrists. It is conceivable that some of them might have been more guarded in their responses concerning the attitude they adopted towards the prudence of women, particularly with severe illness, contemplating having children. Whilst acknowledging this possibility, I don't have clear evidence on whether this would have changed the results substantively.

#### **4.1.3.2 Strengths and limitations of the study with health professionals**

Data presented here represents the first time psychiatrists had been interviewed specifically about their treatment of women with BD regarding pregnancy issues, as

the two studies on professionals' views described in the meta-synthesis (Chapter 2) were concerned solely with postpartum psychosis (and they both used the same dataset from interviews with only 9 psychiatrists in Sweden). Though the number of general psychiatrists was small at 14, it represented a reasonable spread in terms of working environment and geography, with 43% of the sample working outside urban centres, including rural settings such as Somerset and Fife. The sample was representative in terms of gender and ethnicity (57% male, 43% female, 14% non-white British).

The focus group was aimed at specialist perinatal mental health professionals and included representatives from all major specialist perinatal mental health professions: psychiatrists, psychologists, midwives, Health Visitors and obstetricians. A focus group has the advantage of being a dynamic communal process which generates a productive exploration of the subject matter and can identify significant issues which other members of the group can confirm or critique (Gibbs, 1997).

Among non-specialists who come into contact with this group of women, it would have been instructive to hear from GPs as well as general psychiatrists. The former constitute the first line of contact for many women with BD seeking pregnancy advice, and this thesis contains many comments from women about their interaction with GPs (Chapter 3) so it would have been preferable to hear from professionals themselves on how they approached such consultations. In an effort to include GPs, I contacted the Royal College of General Practitioners to ask about any upcoming opportunities when groups of their members would be present such as conferences, large meetings etc. but unfortunately no time was available for this project. I also invited the RCGP's Perinatal Champion, Dr. Judy Shakespeare, to the focus group for perinatal specialist health professionals that I organised at the Marcé Society conference in Swansea but, though she accepted, she was unable to attend on the day. It is not possible to say what impact the inclusion of GPs would have had on the resultant themes but on reflection the lack of a perspective from primary care must be viewed as a limitation of the study. However, this thesis represents the first time the views of general adult psychiatrists have been recorded on the subject of pregnancy decision-making for women with bipolar disorder, or indeed any other mental illness.

## **5 Women with Bipolar Disorder and Pregnancy: factors influencing their decision-making regarding treatment: a comparative analysis of the views of women and health professionals**

### **5.1 Introduction**

This is the first study to look at the views of *both* service users and mental health professionals in relation to their experience of decision-making around pregnancy with a diagnosis of bipolar disorder. A detailed account of the exploration of women with BD's views has been presented in Chapter 3. Chapter 4 sought to investigate the perspective of professionals treating this population. This chapter describes a comparative analysis of the themes and sub-themes identified in order to see more clearly where they overlap or diverge and understand why these differences arise.

### **5.2 Method**

As discussed in Chapter 3 (3.3.2), data was gathered via semi-structured face to face interviews with 21 women recruited from NHS clinics and through the charity Bipolar UK. The views of a further 50 women were gathered via an internet forum (3.2.2). To obtain the views of professionals, I recruited two different samples: 11 specialist perinatal mental health professionals (5 psychiatrists, 2 psychologists, 1 obstetrician, 1 midwife, 1 health visitor and 1 psychiatric nurse) who attended a focus group (4.1.1), and 14 general adult psychiatrists, who were interviewed; 11 by telephone, 3 in person (4.1.2). Of this group, 8 were based in London, 6 elsewhere, including rural Somerset and Fife. Eight were male and 6 female (average age 35) and they worked in a variety of settings: inpatient, urban and rural community teams, a psychosis team, woman's PICU (Psychiatric Intensive Care Unit), general adult liaison and assertive outreach. The

sample didn't include as many psychiatrists from CMHTs as intended as few responded to my invitation.

### **5.2.1 Analysis**

All themes and sub-themes that arose from the women's and professionals' data were re-examined and compared closely with data from the health professionals to identify where and to what extent they corresponded. A matrix was then constructed to give a clearer picture of overlap and discrepancies. There are several types of comparative analysis, such as Glaser and Strauss' technique of 'constant comparative analysis' which compares one piece of data with all others to compare similarities and differences (Glaser and Strauss 2017). This method was employed at earlier points in this project to identify emerging themes in the data from women with BD and health professionals treating them (Chapters 3 and 4). Here, I employ a similar approach but at the level of the themes that emerged in previous chapters from the data of different groups in order to, as Miles and Huberman say, "strengthen a theory, built through examination of similarities and differences across cases" (Miles and Huberman 1994). As the themes from the two groups of professionals were not always the same, I have shown them separately on the matrix to foreground where they agree and disagree to better understand the factors affecting pregnancy decision-making for women with BD.

## **5.3 Results**

Before giving a detailed account of the results of the comparative analysis, I will summarize the key points which emerged. Due to the differences revealed while examining the data, in particular between the specialist health professionals and the general psychiatrists, I have compared the themes and sub-themes across all three groups of participants, as indicated in Table 5.1 below. As the matrix illustrates, there was considerable congruence across all groups in certain areas but also a number of disparities, particularly in the superordinate category of *Contextual factors*. The most

striking feature of the matrix concerns the theme of *Centrality of motherhood* which was of such major significance to women in this study yet did not feature in the testimonies of either group of health professionals. It is also evident that all three groups broadly concurred on the problems with services as currently provided and how to improve them. Some sub-themes were discussed by both women with BD and the specialist health professionals, such as *Fear of being a bad parent* or of *passing on BD*, but not by the general psychiatrists, while others were not raised by women but were considered to be of great importance by general psychiatrists, such as *Capacity*.

The areas of disagreement between the women's themes and those of the professionals reveal the latter groups' focus on the issue of risk and the eight sub-themes where there is a discrepancy between the two groups of professionals (such as economic or cultural factors, capacity or physical readiness) largely reflects the fact that the members of each group operate in a different context and so have different concerns. The perinatal specialists mainly saw women who were passionate about having a child and actively seeking advice on all related aspects of how to achieve that goal, while the general psychiatrists were more likely to see patients still engaged with secondary services with more severe illness and comorbidities where the priority was avoiding relapse or the risk of greater morbidity. There follows a more detailed analysis of the differences and similarities across groups for each major theme.

***Table 5.1: Comparison of themes from women with BD, specialist health professionals and general psychiatrists***

<b>THEMES</b>	<b>Sub-themes</b>	<b>Women with BD</b>	<b>Perinatal specialists</b>	<b>General psychiatrists</b>
<b>Centrality of motherhood</b>		✓	X	X
<b>Contextual factors</b>	Cultural and religious	✓	✓	X
	Social factors	✓	✓	✓
	Economic factors	✓	X	X
	Partners	✓	✓	X
	Timing	✓	✓	✓
	Unplanned pregnancy	X	✓	✓
	Capacity	X	X	✓
	'Super Mum' pressure	✓	✓	X
	Physical readiness	✓	✓	X
<b>Fear</b>	of being a bad parent	✓	✓	X
	of Social Services	✓	✓	✓
	of medication harming the baby	✓	✓	✓
	of becoming ill	✓	✓	✓
	of passing on BD	✓	✓	X
<b>Stigma</b>	Anticipated stigma	✓	✓	✓
	from professionals	✓	✓	✓
	about breastfeeding	✓	✓	X
<b>Experience of services</b>	Access to information	✓	✓	✓
	Communication	✓	✓	✓
	Need for training	✓	✓	✓
	Need for better co-ordination of services	✓	✓	✓

### 5.3.1 Centrality of motherhood

This theme reflects the enormous importance women attached to having children (3.3.2.1). It is striking that the strength of women's desire to become mothers and the relative importance of that when weighing up the various risks associated with pregnancy were not mentioned by either group of health professionals. One woman in this study, for example, said that having a second child "wasn't worth" the risk of being ill and disrupting her family's life to such an extent, whereas others were willing to face several months in hospital and many sessions of ECT because they felt so powerfully motivated to have another child. It would appear that professionals were almost entirely focused on the risks that pregnancy presented for women with BD rather than any benefits to their life as a whole, though their different professional backgrounds and the contexts in which they worked reflected different concerns. Perinatal specialists stressed the importance of emphasizing the risk of relapse and ensuring women and partners were fully aware of the potential dangers:

*'I think people often come very worried about what would be the effects of medication but that's part of the weighing up isn't it? What's the effect of deciding to come off your medication and what is the evidence we've got for that and what's the risk in that individual woman really.'*

General psychiatrists were more focused on how to keep severely ill women from suffering a serious, potentially dangerous episode and how stopping or switching medications due to pregnancy might affect that:

*'They're on something like Lithium or Sodium Valproate and you're desperately trying to get them to stay on it - that can be a real problem if you open up the pregnancy discussion...and also the contradiction of "You're not bloody changing the meds at the moment because you're far too unstable to do that." P10*

### 5.3.2 Contextual factors

As can be seen from the matrix (Table 5.1), there were numerous contextualizing factors which had a bearing on decision-making. Such factors are also relevant to women without BD when they think about having children but for those with BD they can assume a greater significance. This superordinate theme contained a variety of factors described by women as having a background influence on their decision whether to have a child and how and when to go about it. Most sub-themes did not emerge from the data of all three groups and the discrepancies will be discussed below. The two which *did* feature in the responses of the women and both professional groups were *Social factors* and *Timing*.

#### 5.3.2.1 Social factors

Social factors played a role in decision-making for many women. Being conscious of the possibility that they might become ill, especially postnatally when their baby would need 24-hour care, women with BD spoke about their awareness of needing a great deal of support, from family, friends and perhaps services. As participant 14 said [when considering getting pregnant]: “you’ve got to think ‘Is your family supportive?’”. Another said:

*‘My Mum has been amazing ...she actually did the night feeds and stayed on a camp bed in the front room ...She’s been a huge source of support.’ P13*

It was recognised how important this could be in preventing an episode from escalating, considering the crucial role of sleep in BD. As participant 5 said:

*‘If it gets too much where I need to sleep then I will just send baby to my Auntie, the one from Bangladesh ...and I’ll catch up with my sleep’.*

Both groups of professionals did refer to a woman’s social circumstances as a factor to take into account, in as much as she would need help with the baby and practical as



well as emotional support from friends and family as detailed by women in this study. A perinatal psychiatrist in the focus group asked:

*‘So what are her support structures? What actually happens when she gets ill with her bipolar illness? So what is the fallout of her not staying well?’*

General psychiatrists were aware of such factors but more often saw women who lacked a social network:

*‘I have to say ‘We’ll need to make sure you’ve got additional support ... and that might involve social services’ P10.*

#### **5.3.2.2 Timing**

*Timing* was the other contextual factor which was discussed by all three groups. For the women, this related to two issues: how long it had taken them to feel confident to make the decision to have a child and their consciousness of time running out, and how that decision had been delayed by receiving poor information on what they needed to do to prepare for pregnancy (3.3.2.5.1.1). Several women raised the issue of having been given very little or no information about the issues around pregnancy and BD after receiving a diagnosis. They expressed regret that they didn’t know the problems with various medications and the time it might take to change from one to another before conception, especially as problems getting a diagnosis and suitable treatment had often taken many years so their “biological clock was ticking”. A woman on the e-forum made the point that this issue should be discussed when deciding what long-term medication to take, as she had been put on valproate and then had to switch to quetiapine, which took time and caused her more stress:

*‘I do feel it would have been more beneficial if women of child-bearing age were initially started on a drug that’s safer in pregnancy so that if an accident were to happen or someone did want to start a family there would be less risk.’ [e-forum]*

Timing was also a consideration for the specialist health professionals; they were concerned that women only had an opportunity to discuss the issues around BD and pregnancy when they were trying to become pregnant or were already pregnant. They argued that it would be far preferable if women had had at least a preliminary discussion of the issues *before* they reached that stage so they were aware of the serious effect pregnancy could have on BD and had a longer time to consider their options. This issue of timing was in principle generally endorsed by the general psychiatrists, though two male psychiatrists said they did not always talk to patients with BD of childbearing potential about pregnancy (P5 and P11), as this quote illustrates:

*'Frankly it's not a priority, there are so many things we have to fit in to the short time we have ...it's not something I would ever think to talk about, I have to say.'* P11

Various other reasons were also given from not having enough time in the consultation (4.1.2.2.2.1) to concerns that it might 'scare' women and discourage them from taking their medication:

*'I think the biggest challenge ...is the timing of when we do that. If you're seeing someone who's 23 or younger, making the initial diagnosis ...it can seem quite strange. You don't want to terrify them.'* P7

One interviewee said that other members of the care team disapproved of having such a conversation soon after a woman had received a diagnosis of BD because they were trying to 'instil hope' and flagging up the medication's teratogenic risks would run counter to that. Notably all the female psychiatrists in the sample (6 out of 14) said they prioritized talking about the risks of pregnancy with their female patients of childbearing age. Female psychiatrists were more conscious of the constant possibility of pregnancy; as one explained:

*'Absolutely ...it's the first thing that I think...the first thing that I am aware of when I see a woman is that she can have a baby.'* P10

### 5.3.2.3 Cultural and religious factors

Eight women interviewed in this study were Black, Asian or mixed race and five (including 2 Caucasian) women were from strict religious backgrounds and some said that cultural and/or religious factors were important to them when thinking about pregnancy (3.3.2.2.1). This was also raised in the focus group of perinatal specialists:

*'In terms of decision-making, understanding the family and the cultural pressures on the mother to have a baby ... I certainly think, particularly with women from different cultures, understanding the other influences on her pregnancy intention, the kind of decision-making processes, is also important.'*

General adult psychiatrists did not refer to this specifically as a factor, being more focused on the risks pregnancy might present to their patients' mental health.

### 5.3.2.4 Economic factors

Some women who were concerned that, because having BD had had such a negative effect on their career and employment prospects (as well as sometimes running up debts when manic), they would not be able to afford to give their child the lifestyle they would have wanted to (3.3.2.2.4). For example, participant 10 worried that:

*'[Because of] my illness, I haven't worked for years and ...I come from quite a secure background and ...I had ballet and piano lessons and things like that and ...I wanted to re-create that...[but] due to my illness ...I have a great deal of doubt whether I could manage it.'*  
P10

Neither group of professionals referred to this theme.

### 5.3.2.5 Partners

Only the perinatal specialists talked about the importance of partners, which many women had focused on (3.3.2.2.7.1 "He's my rock"). Participant 12 said she was very lucky to have her husband because:

*'It's such a hard decision and [you need] someone who you can trust ...to think things through rationally.'*

But for others, they felt unable to pursue their desire for a child because “my husband wasn’t prepared to take the risk” (3.3.2.2.7.1). Specialist health professionals agreed that it was very important to involve partners in pregnancy decision-making and some spoke of actively encouraging partners to attend meetings to ensure they were ‘on board’ with plans. It was pointed out that some partners could have poor awareness of the seriousness of the risks, especially if they had never witnessed their partner being severely ill, so they needed to be given a careful explanation:

*'I find sometimes the partners have no knowledge at all and the woman is doing this by herself, so I really like both to buy in to whatever we're talking about'.*

General psychiatrists did not discuss the partner’s role; many of them worked in settings with women who were in and out of hospital repeatedly and didn’t have partners.

#### **5.3.2.6 Unplanned pregnancy**

The sub-theme *Unplanned pregnancy* did not arise in the women’s data. General psychiatrists reported that they were more likely to see women when they were already pregnant by accident than to give preconception advice and also were concerned that vulnerable women who were incapacitous were more likely to become pregnant by accident. The only member of the focus group of specialists who raised this as an issue was a member who spent only a portion of her time as a perinatal psychiatrist and the rest as a general adult psychiatrist. She said it was a ‘big issue’ for her and she always ensured she talked to all women with BD of childbearing age about pregnancy, especially as their behaviour when manic could leave them more vulnerable to unplanned pregnancy. This concurred with the experience of the general psychiatrists who were interviewed: they placed greater emphasis on the heightened risk of unplanned pregnancy for this population and the need for contraception advice.

### 5.3.2.7 Capacity

This theme did not arise in either the women's or specialists' data but was raised frequently by the general psychiatrists some of whom worked in settings caring for more severely ill women such as urban outreach and high dependency units. Those general psychiatrists caring for women who lacked capacity reported that it could be extremely difficult to convey to them the delicate balance of risks involved in this area of decision-making (4.1.2.2.1.4). Because women they saw were often incapacitous, they said they had to carefully time conversations about the teratogenic effects of medications to ensure their patients understood what they were saying:

*'...the vast majority of patients do not have capacity at the time of the initiation of the treatment plan to consent to decisions around their medication. We would ...keep talking to them, but their ability to take any of that in, retain it, and weigh things up will fluctuate.'*  
P1

### 5.3.2.8 Social pressure to be a 'Super Mum'

Women described feeling pressurized by society's focus on the need to be a 'super Mum' or 'perfect mother' and worried that, as a woman with BD, they might not be able to live up to this ideal:

*'I know that if I did have a child I would want to be the best Mum, you know, I'd want to be Super Mum and ... I can imagine that I would exhaust myself and there's a lot of danger in that'.* P18

Anxiety over this exacerbated their feelings of guilt and inadequacy if they were ill and had to be separated from their baby for weeks or months after the birth. The harmful effect of this excessive guilt was emphasized in the specialists' focus group, with the MBU psychologist and specialist health visitor both saying it was something women really struggled with and needed psychological help to overcome. A perinatal psychiatrist also referred to the toxic effect of such feelings, stating that he saw 'reassurance' as a major part of his role. General psychiatrists did not bring this issue up.

### 5.3.2.9 Physical readiness

Women in this sample who were seeking preconception advice were also aware of their physical health:

*'If you can't really look after yourself how are you going to look after a kid? ...you've got to think about your health, ...your nutrition.'* P14

The focus group of perinatal specialists recognised that attention needed to be paid to women's physical health status, calling for the adoption of a 'holistic approach' to preparation for a healthy pregnancy (4.1.1.2.2.2.5). They also raised the danger of 'diagnostic overshadowing' or the risk of missing physical illness because of an over-concentration on mental health risks, pointing out the need to remember the 'normal anxieties' that women have about pregnancy:

*'...the bipolar disorder's really important to be planning for and that's why they're seeing me, but there may well be other things going on in terms of concerns about medication and metabolism and all those sorts of normal things that everybody's got to be thinking about, blood pressure and whatever else, difficult delivery, all sorts of things.'*

The general psychiatrists interviewed did not raise this issue but did refer to the high level of comorbidities in this population (particularly substance abuse and diabetes) as a further complicating factor when discussing the possibility of pregnancy (4.1.2.2.2.2.9). Their concern at the very high risk of serious psychiatric relapse in this group outweighed other considerations:

*'We have a number of women on our caseload who have diagnoses of bipolar affective disorder and schizoaffective disorder ... most of them have fairly significant risk histories ...some with very significant forensic histories and many have co-morbid issues alongside their mental disorder, particularly substance misuse disorders and personality disorders.'* (P3)

### 5.3.3 Fear

#### 5.3.3.1 Fear of being a bad parent

Anxiety over their capacity to 'match up' to society's ideal of a mother, described above, overlapped with the first sub-category of *Fear: Fear of being a bad parent*. This emerged as a separate theme as women were not only worried about being stigmatized by professionals and society at large as described above, but they were also anxious that their illness might prevent them from being as good a mother as they wanted to be (3.3.2.4.3). As a woman on the e-forum said:

*'I spent a lot of time worrying ...that I am a bad mother due to mood issues.'*

The specialist group picked up on this anxiety. It was focused on by a psychologist who worked chiefly with women postnatally. She said many women she saw in the MBU in the months after the birth:

*'...express a lot of anxiety about ...how their mental health problems have influenced their care of the baby ...they are very anxious.'*

General psychiatrists, who rarely saw women postnatally, did not mention this as a factor.

#### 5.3.3.2 Fear of Social Services

A widespread fear that all three groups did comment upon was the fear of Social Services' taking the baby away, expressed many times by women on the e-forum:

*'I was terrified of seeking help, as I thought if I revealed how I felt she would have been taken into care.'* [e-forum]

All groups concurred that this was a significant factor in women's decision-making, and one which not only made frank exchange difficult but also caused 'disproportionate'

levels of stress for women approaching professionals for advice. A psychologist in the group said:

*'I know that a lot of women are just so frightened that if they disclose anything they'll instantly be referred to Social Services'.*

Perinatal specialists said they were familiar with encountering this and tried to reassure the majority of women that removal of the baby by Social Services was extremely unlikely to happen but for those with little or no social support and comorbidities like drug and/or alcohol abuse, they had to discuss the need to involve Social Services to make an assessment (4.1.2.2.2.2.9). This approach resembled that of the general psychiatrists who reported seeing women for whom Social Services involvement was not so rare. Several spoke of women being "very scared" of Social Services, so much so that they were hesitant to raise the subject for fear of their patient leaving the meeting:

*'I think people are terrified of social services. I have to say that being a doctor and trying to be reassuring about social services is completely ineffective ... People actually walk out if you mention social services.'* P1

However, if the chances of keeping the child were low, they felt they had a responsibility to tell them that:

*'First I'll have a really long conversation with them about how realistic this [having a child and keeping it] is. ...Quite a number of our women have had children taken into care and some have had several children taken into care. And so you have to have an honest discussion about that making it very clear that when you get pregnant children and family services will be involved from the very beginning and there will be very close liaison with us, the midwives and... sometimes you have to say, you know, the chances of them keeping that child are low. I think you have a responsibility to tell them that.'* P3



### 5.3.3.3 Fear of harming the baby

Apart from dread at the prospect of having their baby taken away or of becoming very ill, the biggest fear experienced by women with BD contemplating pregnancy was that they might harm their unborn child by taking teratogenic medication, as participant 16 said:

*'I take medication and I'm thinking that might affect the baby, harm it in some way, so sometimes I think I'm better off not having a baby'.*

The specialist focus group confirmed that these were the most important considerations for the majority of women they saw. As this perinatal psychiatrist said:

*'the questions that people don't ask are often around sheer terror ...my experience is that the ultimate core symptom of fear is around damaging the child.'*

Both clinicians and women themselves described the discussion around the risks and benefits of continuing medication as a very complex and emotionally loaded one, often coming down to whether fear of becoming ill outweighed fear of potentially harming the baby. The professionals acknowledged that whatever was said in the consultation regarding the high risk of relapse, many women chose to stop taking their medication because their overriding concern was to protect the baby from teratogenic risk.

*'It can be overwhelming and women will not take anything because they're so frightened that whatever they do ...they might do something terrible to their baby'.*

Focus group professionals spoke of the difficulty of adequately conveying the woman's risk of becoming ill when off medication – a situation which would itself pose risks to the unborn child were she to become psychotic. The general psychiatrists in this study were also very concerned not to “engender fear” by describing the available research on the teratogenicity of medications in such a way that would “terrify”

women into stopping their medication, with one interviewee describing this as “the biggest challenge”.

*‘I find it difficult because ...it’s sometimes difficult to convey the degree of uncertainty around the risks of taking or not taking medication and so on.’ (P9)*

#### **5.3.3.4 Fear of becoming ill**

The fear of becoming ill was also very prominent for many women, particularly those who had already experienced a postpartum psychotic episode:

*‘I’m very fearful about reducing or coming off my Carbamazepine ...I’m fearful at the possibility that I would suffer with postpartum psychosis. [pause] ... God actually I can barely even think about that.’ P6*

In relation to this it was useful to have data from women on the e-forum who attested to the fact that suffering a severe postpartum psychosis had deterred them from contemplating having any more children, as only one interviewee had stated this:

*‘It was just too difficult for everyone ...it’s a fairly dead cert that I would become ill again and ...it was just too much of a damaging experience.’ P13*

Specialist professionals were very attuned to this and prepared to talk through the frightening aspects of the birth and postnatal period to clarify what might be done differently if another pregnancy was desired and what preparations needed to be put in place (4.1.1.2.2.1.2). General psychiatrists referred to the risks of relapse rather than to women’s fear of it happening, but were principally concerned about how best to convey those risks, particularly if their patients were ill at the time of consultation:

*‘I think it’s very important to be upfront with patients about how high risk it is, but whether or not I do, I don’t know. There’s a balance to be struck between wanting people to have all the information but not scare them away from services.’ P9*

#### **5.3.3.5 Fear of passing on bipolar disorder**

This was another sub-theme of 'Fear' that did not arise in interviews with the general psychiatrists but did in the specialists' focus group: the concern that women would be passing on the disorder to their offspring. Genetics were raised as an important factor for some women in this study, particularly by women posting on the e-forum.

*'Like others I am scared of the rather high statistic I believe it's 15% more likely to get Bipolar if a parent has it. That scares me that I may be bringing life into the world that may suffer so strongly. Something I wouldn't wish on anyone let alone my own flesh and blood.'*

Two of the perinatal psychiatrists in the focus group said this was something that rarely came up in consultations, though the psychologist on the MBU said it was a significant issue for many of her patients:

*'They are very anxious ...and can be crippled with guilt and worry'.*

The specialist Health Visitor in the group agreed that it came up a lot when she spoke to women once they were at home, sometimes months after the birth.

### **5.3.4 Stigma**

Women felt stigmatized not just for having a mental illness but also for thinking about being a *mother* with mental illness, and professionals were aware of the stigma experienced by women and the effects it could have on their interactions with clinicians, the only difference being over stigma in relation to breastfeeding.

#### **5.3.4.1 Anticipated stigma**

Women in this study expressed the fear that people would think that they should not have children and would perhaps think they would necessarily be 'bad mothers' and this led some to anticipate they would be discriminated against. One interviewee said:

“It’s almost like: ‘We shouldn’t really let the mad people have children’” (P3) and Participant 21 said:

*‘My worst fear is people thinking I’m less capable because I’ve got bipolar ... I don’t want people to think ... ‘she won’t be able to look after her kids’ ...that’s a horrible feeling.’*

Women anticipated that they would be treated differently by health professionals because of their BD diagnosis (3.3.2.3.3). This fear was realized in the case of one interviewee who had had a diagnosis of depression for her first three pregnancies but found staff attitudes very different when her diagnosis changed to BD:

*‘I feel very watched ...whereas before I would talk so openly to professionals about what I was going through ... I feel almost like I’m watching what I’m saying to professionals now that I’ve been diagnosed.’ P17*

Anticipated stigma was also highlighted as a problem by the focus group of perinatal specialists, particularly in relation to treating women postnatally. It was noted that women could be extremely worried about being treated in a stigmatized way and the MBU psychologist said this made some “feel very anxious about who they tell about their mental health problems”. General psychiatrists also recognised this problem and the detrimental effect it could have on effective treatment:

*‘I’ve met quite a few people who think that just because they have a diagnosis people are going to perceive that they shouldn’t be having children. I think that’s a worrying thing too – whether they’re less likely to be honest about things and so on’. P9*

#### **5.3.4.2 Stigma from health professionals**

Some women anticipated stigma because they had experienced it from health professionals before. A number reported discriminating attitudes towards them (see 3.3.2.3.3) while others spoke of a more generalized consciousness of being stigmatized:

*'In hospital ... even with the midwives - I still felt there was this kind of thing ... because I have bipolar. ... The perception they make me feel that they have of someone who has bipolar - that you're kind of different to everyone else.'* P17

In this study, both perinatal specialists and general psychiatrists spoke of the effects of stigma on their dealings with women with BD and the efforts they made to counteract it. A perinatal psychologist said she was "aware that women might feel very stigmatized" and two general psychiatrists (P2 and P9) said they were conscious that many women had encountered stigmatizing attitudes from fellow professionals and they tried to treat women differently, as Participant 2 expressed:

*'What women find difficult is when they feel that the attitude from their mental health provider is "You shouldn't be having children. You can't... I'm not prepared to discuss this with you," that you're being somehow irresponsible if you want that. What I want with my patients is to know that you see them as a whole person not just their mental illness, and if they want to have a family then they can but there is extra support there we'd really like to give and that it's not ever a kind of dictating thing. I think you can do it very easily in a human way, not in a stigmatizing way.'* P2

#### **5.3.4.3 Stigma related to breastfeeding**

This was the only sub-theme of *Stigma* where a difference between groups arose. Stigma around breastfeeding was referred to by both women and the specialist professionals, though not the general psychiatrists, few of whom had experience of looking after nursing mothers. Many women who were unable to breastfeed because of the medication they were taking, reported how guilty they were made to feel by staff, especially midwives, constantly asking them why they weren't breastfeeding their baby (3.3.2.3.4) As this woman said of her time on the postnatal ward:

*'I detested staying [on the postnatal ward] ...Particularly because being on lithium, I was bottle-feeding and therefore I was a child of a lesser god and so was my child. ...I got a lot of 'Why aren't you breastfeeding?' 'Why?' ... and it was like ...do you want to not talk to me like that? P9*

Members of the professionals' focus group recognised that this was a problem for women with BD, particularly if they were stable on lithium which is not recommended when nursing a baby:

*P1: 'I think it's fine [if a new mother wants to bottle-feed] because sometimes they feel very pressured that actually they should be breastfeeding.'*

*P2: I agree. They feel very guilty.'*

The specialists also emphasised the other benefits of bottle-feeding for this group, which women themselves had raised, such as enabling them to have better control of their sleep, though there was a difference in attitude among different professional groups as the specialist midwife thought it was important to support women as much as possible to breastfeed and stated that breastfeeding actually promoted sleep because of the release of prolactin.

### **5.3.5 Experience of Services**

Across all groups of participants in this study, service users and clinicians, three major sub-themes emerged in this area: Access to information, Communication and Need for planning and service co-ordination.

#### **5.3.5.1 Access to information**

The interviews and data from the e-forum reported in Chapter 3 demonstrated that access to information was a major problem for many women with BD contemplating pregnancy. When their condition had stabilized and they were keen to look into their options regarding medication and treatment during and after pregnancy, most reported being unable to talk to a specialist perinatal psychiatrist (because such a service was not available in their area). Many reported receiving poor information from their GP or sometimes from a general psychiatrist:

*'I have not found anything useful or supportive from [discussions with health professionals] as nobody has seemed to be "qualified" to discuss this with.'* [e-forum]

Members of the specialist focus group corroborated this finding and described how this caused them extra problems when consulting with women because they often had to correct the false information they had been given by their non-specialist colleagues. They reported that this was not only very confusing for women and their partners but also added to their stress over making the 'right' decision and did nothing to build a woman's trust in the health professionals treating her:

*'It can be tricky in that situation where the woman's been given some advice, mainly by a general psychiatrist ...and we say, well it's not quite as straightforward as that. But you don't want to raise lots of anxieties, so it's that balance of how you deal with information that's been given by various different professionals.'*

Several women reported resorting to the internet to try to do research themselves as so little information was available to them; participant 13 described "scrabbling around" online "trying to do research myself".

The specialist group discussed the fact that many women they saw had resorted to searching the internet for answers but reported that this was rarely helpful as the information they found there was often incorrect and was sometimes presented in a frightening way which increased their patient's anxiety, as one perinatal psychiatrist said:

*'You do your best to allay anxiety and contain and do what you can, then they go home and ...google it'*

This chimed with evidence from women:

*'searching for things on the internet - you come across all sorts of unhelpful things because random people... decide to post something and ...you think 'Oh my goodness, am I going to end up like this person?'* P3

General psychiatrists interviewed in this study did not raise the issue of women searching for information on the internet but they acknowledged that they weren't familiar with the relevant research: they either consulted a specialist service, referred the patient on if possible, or looked up the relevant guidelines for advice. The specialists' knowledge of other sources of information and support in the Third Sector and on various websites such as that of the Royal College of Psychiatrists, also differed from that of the general psychiatrists: the former said they used such resources regularly but many of the latter group said they were unaware of other sources to which they could refer people. Women in this study fell between these two extremes, with a minority of women saying they had located some helpful information of this sort, mainly via internet searching.

#### **5.3.5.2 Communication**

Women in this study reported multiple examples of communication problems with health professionals. For example, Participant 3 said she:

*'felt very much that they weren't supportive of me trying to have a baby... I got a lot of negative information ...'*

Specialists and general psychiatrists alike were conscious of the need to communicate the risk/benefit ratios as well as possible, though several in the latter group said they found this challenging, particularly the need to individualize advice:

*'You can quote figures but obviously applying that to an individual is incredibly difficult and to actually interpret that in the context of that person's illness and how they've coped with symptoms' P7.*

It was evident from the data gathered in Chapter 3 that women were often focused on how they could avoid any risk of harm to the fetus by coming off their medication while *hoping* that they would not get ill as a result, whereas both groups of clinicians showed a greater awareness of the likelihood of relapse during or immediately after pregnancy. The specialists emphasized the importance of conveying the level of this risk to their patients who didn't want to acknowledge it (indeed some women who *had*



become ill perinatally admitted they had been in denial about this). As this participant who had been hospitalized after suffering a postpartum psychosis with her first child, said about her second pregnancy:

*'...I didn't have a plan at all. I think I was in denial about the idea that it might happen again.'* P2

The general psychiatrists' views were dominated by their concern to keep their patients well: they were even more acutely aware of the risk of relapse than the specialists because they were often dealing with individuals who had a much more serious and high-risk profile.

*'When you've got someone who's actually still quite unstable, they may be still using drugs, they've got a chaotic lifestyle and they're on something like Lithium or Sodium Valproate and you're desperately trying to get them to stay on it - that can be a real problem.'* P10

Because of this, some said they were very careful to time their conversations on teratogenicity of medications so as not to unduly alarm a woman who – often while lacking capacity – might feel compelled to stop her drugs abruptly, with possibly dangerous consequences. This group emphasized that the gravity of many of their patients' illness inevitably influenced the degree of active collaboration possible while the specialist group, who were generally seeing an euthymic population, described their role as more purely advisory with the decisions left up to the woman (and her partner if applicable).

*'I am usually very clear (I hope) that it's the woman's decision and I am there to help provide information and think through the issues.'*

#### **5.3.5.3 Need for training**

General psychiatrists reported a lack of clinical confidence when advising women with BD on medication issues and perinatal research generally, an acknowledgement that chimed with both women's reported experience of such advice and evidence from the

specialist perinatal professionals (described in 4.1.1.2). Participant 3 said she thought “a lot of [the psychiatrist’s] attitude is to do with a lack of knowledge” and, as described above, women reported being denied information when they requested it, or even being given incorrect information by non-specialists. Such reports were corroborated by the specialist group who said that one of the problems they encountered when advising women was “undoing” the advice they had received from others:

*‘It can be tricky in that situation where the woman’s been given some advice, mainly by a general psychiatrist ...and we say, well it’s not quite as straightforward as that ...you don’t want to raise lots of anxieties.’*

General psychiatrists in this sample agreed that their knowledge of the relevant research on different medications could be improved if they received more training on this subject. As one interviewee pointed out, there are numerous ‘specialist’ areas of psychiatry and most psychiatrists had received scant training in this area, leading to uncertainty:

*‘I think [psychiatrists] worry that the information they thought they knew changes quite quickly and [they] don’t want to be the person who prescribes the medication that causes a problem either in breastfeeding or pregnancy’. P9*

#### **5.3.5.4 Need for better co-ordination of services**

A topic on which all three groups, women with BD, specialist professionals and general psychiatrists, agreed was the need for better co-ordination of services to identify women who needed support and then ensure they received that support. Women interviewees spoke of being switched between Community Mental Health Teams (CMHTs) and worrying about having yet another set of professionals to engage with after the birth who didn’t know them.

Building a trusting therapeutic relationship with health professionals is very important for all psychiatric patients but this lack of continuity of care was reported as being

particularly difficult for people with BD as fluctuating mood is at the heart of the disorder and so women saw it as particularly important for clinicians to be able to compare their mood over time.

*'I've been switched to a new mental health team as the early intervention service only work with you for so long. And I had a good relationship with her [her previous contact] I could just text her anytime ...change is really hard for me and ...I'm also scared about after the birth as I can get worse ...' [e-forum]*

As they had often had to have several appointments with various branches of maternity services, women also complained of having to repeat accounts of their worst episodes again and again – often to staff with little or no psychiatric training or understanding of their condition. Some reported this could be traumatic or even triggering. The focus group of perinatal specialists corroborated this point (4.1.1.2.2.2.4). They saw it as essential to “share information and talk about risk and relapse signatures”. The specialist midwife in the focus group said “close liaison between the midwife, the obstetrician and the mental health team is vital for women with bipolar disorder”. She called for better organization of services so there was a clear pathway which minimized the necessity for such repetition and ensured, as much as possible, that women with BD were treated by staff with at least some perinatal mental health training.

General psychiatrists referred to the difficulty of not being able to develop a therapeutic relationship with patients due to the way services were structured. More than one interviewee talked about the need to build a ‘long-term relationship’ with their patient in order to establish the trust needed to share the complex decision-making around pregnancy, but explained that the system meant that they only saw the most severely ill patients or when they were in extremis, making the development of rapport extremely difficult:

*'The pressure is that the moment someone is out of an acute episode they get discharged straight back to their GP and [if they have another episode] the GP then refers them back to you. It's shocking. And in terms of building up that trust and rapport if you*

*only see your psychiatrist when you're in extremis, how do you get a view that this is somebody who knows you and you can trust to recommend things?' P2*

They also referred to communication problems between general practice, mental health services and specialist perinatal provision. Some general psychiatrists complained that they had difficulty accessing advice or support from specialist perinatal services because they were so thinly spread, reinforcing criticism from women in this study that such services, including the provision of Mother and Baby Units, aren't evenly distributed throughout the country.

All three groups endorsed the need for a jointly arrived at care plan. The specialists were unanimous that it was crucial to providing good care: it needed to be detailed and include matters such as who would look after any older children or take responsibility for decisions about the baby if the woman should become psychotic; medication preferences in pregnancy, post-birth and in relation to breastfeeding, and how to help new mothers get their sleep (for example by providing private rooms).

*'I think the earlier you start that conversation the more you give women a chance to think about it and involve other people [so that] ...if a relative comes over from a different country, or someone decides to move in with them, all those things can be set up.'*

The health visitor in the group also stressed the need for her service to be included in the forward planning as they would need to follow up with care once the woman returned home. The group viewed the formal production of a plan as a practical way to help women and families navigate their way through the 'maze' of appointments and different services, outlining the decisions arrived at, which professionals were responsible for a woman's care at what stages, and how women wanted things to be handled during and after the birth. Those women in this study who had received such a plan or were engaged in creating one, were overwhelmingly positive about its usefulness and its role in engendering confidence that they would receive good care (3.3.2.5.5.2).

*'We now have a plan, and I'm really grateful for [the perinatal psychiatrist]'s summary ... which is incredibly clear, and I've been able to give that to the midwife, my GP and a copy's gone to the CMHT. So I now feel like everybody's singing from the same hymn sheet.'* P3

General psychiatrists spoke about discussing care plans with their patients rather than a specifically *perinatal* plan involving liaison with midwives etc., reflecting the fact that they did not usually see women who were pregnant.

## **5.4 Discussion**

This comparative analysis sought to compare the views of women with BD, specialist perinatal mental health professionals and general psychiatrists on the factors affecting pregnancy decision-making. As the matrix (table 5.1) above illustrates, there was a great deal of congruence across groups, with most differences occurring in the sub-categories of the theme *Contextual factors*. The most striking disparity between women and the professionals treating them was over the importance of the *Centrality of motherhood*, which will be discussed below.

### **5.4.1 Centrality of motherhood**

The most conspicuous result from the comparison of women's and professionals' views was that the major theme '*Centrality of motherhood*', which was so fundamental to women's experience of how they approached making decisions about pregnancy, was not mentioned by either group of professionals. The value women attach to having children has been described (5.3.1), including its particular importance to women with a severe mental illness (2.2.2.2.1.7). Perinatal specialists might be expected to refer to women's strong desire for motherhood as an important factor when deciding whether to have a child as they are seeing individuals who have actively pursued specialist preconception advice. Women in this study spoke of their motivation to become mothers over-riding their intense fear of becoming very ill as a

result (5.3.1). Both groups of professionals spoke about the balance that needed to be struck when discussing the pros and cons of pregnancy and the dangers of stopping medication but the importance women themselves attached to having a child was not weighed in that balance. This is important because women spoke of suffering years of disappointment and delay in starting a family while professionals failed to help them move forward with their strongly held desire to have children (3.3.2.5.4.1).

#### **5.4.2 Contextual factors**

Seven categories under *Contextual factors* described topics that did not emerge as sub-themes for all three groups. For example, women raised issues related to how their illness had affected their economic status. They said this impacted their decision of whether or when to have a child, as they would not be able to afford to give their child the lifestyle they had hoped to. This is in line with research that has demonstrated that individuals with BD are more likely to have difficulty maintaining regular employment (Marwaha et al. 2013), and that they are more likely to get into debt (Kleinman et al. 2003). Economic factors were not specifically referred to by either group of health professionals in this study.

Eight women interviewed in this study were Black, Asian or mixed race (38%), and some talked about the way in which their cultural background affected their approach to pregnancy, especially because their communities were more prejudiced against mental illness. This evidence supports findings elsewhere that greater stigma against mental illness exists among some ethnic communities (Corrigan 2004, Ciftci et al. 2013). In the current study, the focus group of perinatal specialists also highlighted the importance of taking cultural issues into account when advising women, but this was not an issue brought up by the general psychiatrists who saw few women for preconception consultations when such an issue might be discussed. Perinatal specialists are more likely to see many women in this situation pre and postnatally and so are more likely to have talked about issues important to them and to reflect on common themes. Women participating in the study also had a lot to say about the support they were given by partners and the specialists agreed that it was important

to involve them in the decision-making process. General psychiatrists did not mention the role of partners, but half of those interviewed were operating in high dependency units and in urban settings so they saw mostly single women and the lack of support they had was one reason why they viewed pregnancy as a high-risk option especially as it increased the likelihood of their child being removed by Social Services (Westad and McConnell 2012, Linz and Sturm 2013). The sub-theme of *Capacity* was also very prominent in the data of the general psychiatrists, whereas the women and the specialists did not raise it. This was a reflection of the more seriously ill women seen by the generalists but it is surprising that the perinatal mental health specialists did not mention it, especially in relation to the increasing use of Advance Directives by people with bipolar disorder to make their treatment preferences known ahead of an episode of illness involving loss of capacity (Hindley et al. 2019, Gergel and Owen 2015).

On the topic of physical readiness, specialists called attention to the danger of diagnostic overshadowing, which has been highlighted in the Confidential Enquiries into Maternal Deaths (Draper et al. 2018). A number of reviews have demonstrated that people with severe mental illness are more likely than the general population to also suffer from physical disorders (De Hert et al. 2011), and a systematic review of premature mortality in bipolar disorder concluded that mortality for all causes studied (including respiratory and circulatory diseases as well as suicide) was elevated (Hayes et al. 2015). People with BD are more likely to smoke (Lasser et al. 2000); abuse alcohol and drugs (Regier et al. 1990); have diabetes (Van Winkel et al. 2008); and suffer a number of other medical conditions from cardiovascular illness to Hepatitis C (Kilbourne et al 2004). Obesity is also a significant problem, in part due to the association of weight gain with many medications used to treat BD (McIntyre et al. 2006, Keck and McElroy 2003). General psychiatrists did not raise 'diagnostic overshadowing' as such but several were concerned with the high number of comorbidities of the women they saw such as substance abuse and diabetes and the barrier this presented to having a successful pregnancy.

### 5.4.3 Fear

Fear of Social Services' intervention was seen as a potent feature of discussions about pregnancy by all groups, corroborating the results of the systematic review (Chapter 2). General psychiatrists saw it as a major barrier to talking to women openly about pregnancy, perhaps because they saw more women who, due to their social circumstances and comorbidities, were more likely to be at risk of having their child removed from their care (Ces et al. 2018, O'Donnell et al. 2015, Howard et al. 2003). All groups also identified the dual fear of harming the fetus by taking medication while pregnant or risking becoming ill by not taking medication as extremely important factors. Professionals recognised that a high proportion of women would stop taking their medication in pregnancy despite the risk of having a serious relapse because their overriding motivation was to protect their unborn child. These findings corroborate research conducted in the UK using a primary care database which found that pregnancy was a major determinant of cessation of antipsychotics (Petersen et al. 2014). Only 38% of women on atypical and 19% on typical antipsychotics were still prescribed the drug in the third trimester.

Both groups of professionals spoke about the difficulties of adequately conveying the nature of the risk of relapse without frightening women, especially the general psychiatrists, who were mostly seeing women with considerably more morbidity than the specialist group. Genetics and women with BD's fears around being a bad parent were not themes in the data of the general psychiatrists though this might reflect the type of setting and phase of illness. For example, members of the focus group who mainly treated women *postnatally* (in particular the MBU psychologist and health visitor) described their importance whereas general psychiatrists reported seeing few women at this time.

### 5.4.4 Stigma

Stigma was also recognised as a significant factor by all three groups, with only the sub-theme of *Stigma around breastfeeding* revealing a difference in that general



psychiatrists did not refer to this subject, explained by the fact that few had any experience of treating nursing mothers. Among the specialists who discussed this issue, it was noteworthy that the specialist midwife had a different attitude to other members of the group (5.3.4.3); she was very in favour of encouraging *all* women to breastfeed and so was more representative of the difficulties women reported encountering with midwives, especially on the postnatal ward (3.3.2.3.4). Both groups of professionals recognised that stigma more generally was a problem that needed combatting because it could deter women from seeking help (Clement et al 2014); discourage them from disclosing relevant information (Wilson and Crowe 2009) and might adversely affect their participation in shared decision-making (Hamann et al. 2017). It is interesting to reflect on the possibility that the increased recognition of risk in the perinatal period for women with bipolar disorder may have had the unintended negative consequence of encouraging an increase in stigma against them in maternity care (see 3.3.2.3.3).

#### **5.4.5 Factors that were themes for all three groups of participants**

Under the superordinate theme *Contextual factors*, the results show that, of the nine sub-themes, only *Social factors* and *Timing* were themes for all three groups. Women were very aware that they might need extra support around them when pregnant and in the early months of motherhood corroborating evidence from other qualitative studies ((Negron et al. 2013, Heron et al. 2012, Doucet et al. 2012). They were particularly conscious of the sleep deprivation associated with caring for a newborn and the detrimental effect that could have on their mental health; a phenomenon that has been evidenced in the literature (Lewis et al. 2018, Bradley et al. 2017, Sharma et al. 2003). Both groups of professionals were aware of the relevance of a woman's social circumstances and how much support she would need.

All groups also discussed at some length the importance of *Timing*. Women with BD wanted to have advance warning of the risks of pregnancy. The need for this was endorsed by the specialists, but they did not bring up the dangers of imparting this information to women at a time when they lacked the capacity to fully comprehend it,

which was a prominent theme in the data of the general psychiatrists (4.1.2.2.2.1) As mania encourages disinhibition and risk-taking behaviour (McCandless and Sladen 2003) and, as a result, women with BD are likely to have more unplanned pregnancies than women without BD (Marengo et al. 2015), this may explain the general psychiatrists' focus on pregnancy prevention for this population (Krantz et al. 2018, Heffner et al. 2012). It was interesting that, when discussing *when* women with BD should be informed of these issues, particularly the potentially teratogenic dangers of their medications, there was a clear gender divide amongst the general psychiatrists. All the female psychiatrists (6 out of 14) stressed the importance of making all women with BD of childbearing age aware of the issues around pregnancy, whereas it was less central for their male colleagues (4.1.2.2.2.1.1). These results highlighted that female psychiatrists were more conscious of both the possibility and importance of pregnancy, perhaps just because they were women themselves.

#### **5.4.5.1 Experience of Services**

There was also overall congruence across groups in this category, though the fact that some topics were prominent enough in the data of all three groups to justify classification as a sub-theme hides some important differences. For example, under the sub-theme *Access to information*, women with BD and members of the focus group were talking about the *lack* or poor quality of information for women whereas the general psychiatrists were more focused on the problems they themselves encountered in accessing and interpreting the research evidence. The fact that, unlike the specialist group, the general psychiatrists lacked knowledge of where to signpost patients for further information or support, revealed a gap in services that would be straightforward to fill. Also, the way in which the two groups of professionals communicated the information women and their partners needed to make pregnancy treatment decisions was subtly different. Studies have demonstrated that, generally, women over-estimate the teratogenicity of drugs in pregnancy (Bonari et al. 2005, Einarson et al. 2003, Nordeng et al. 2010) so both groups emphasized the need to convey the delicate balance between the risk to the baby versus the dangers of becoming unwell but while the specialists were more focused on providing

reassurance and support, the general psychiatrists were more acutely aware of the need to avoid a relapse. This is likely a reflection of the greater morbidity of the women for whom they were caring, especially those working in high dependency settings. There was a consensus among all three groups that more training in perinatal mental health was needed for general psychiatrists and GPs but also for other professionals with whom women were likely to come into contact, such as obstetricians, midwives and health visitors, a result that has implications for practice, discussed below. There was a similar degree of unanimity on the need to improve the integration of services to better identify women who required support and then make sure they received a degree of continuity of care. This echoes the findings of an integrative review synthesizing professionals' experiences of working in collaborative models of perinatal care for women with mental health problems (Myors et al. 2013).

#### **5.4.6 Strengths**

This comparative analysis of professional and service user views on the factors influencing pregnancy decision-making is the first to bring together views from both perspectives on how women with BD approach these life-changing decisions. The two other studies which included the views of women with BD on pregnancy planning, Stevenson et al. (2016) and the Dutch study Stevens et al. (2017) which reported the views of 8 and 12 women with BD respectively, did not include the views of professionals, so this thesis adds to the literature in this area.

It was also a strength that a broad spread of women in terms of age, race and stage in the decision-making process was recruited, and that the data from the 21 one-to-one interviews was supplemented by the contributions of a further 50 women via an internet forum. Considering the professional perspective, it was an advantage that the voices of a cross-section of specialists who are involved in advising women, from perinatal midwives and health visitors to obstetricians and psychiatric nurses, were heard in addition to perinatal psychiatrists. Conducting a focus group with these specialist professionals enabled a rich interactive discussion on the various factors influencing decision-making at this time and the geographical spread of participants

added a useful dimension. It was valuable to also include the data from 14 interviews with general adult psychiatrists as, though the methodology used was different, their data led to a greater understanding of issues raised by both women and specialists. The sample was representative in terms of gender and ethnicity (57% male, 43% female, 14% non-white British). As far as I am aware, this was the first time data had been gathered from psychiatrists specifically about their treatment of women with BD regarding pregnancy issues. In the review reported in Chapter 2, only two papers reported the views of psychiatrists – perinatal specialist psychiatrists - using the dataset of a total of 9 interviewees, and these papers focused exclusively on treating women with postpartum psychosis (only 50% of whom are likely to have BD). Furthermore, these studies were not concerned with preconception issues, which is the main focus of the current study so this thesis is addressing a gap in the literature.

#### **5.4.7 Limitations**

As highlighted previously (4.1.3.2) it would have been preferable to also elicit the views of GPs, so their absence from this analysis must be seen as a limitation. The sample of general adult psychiatrists might be criticized for being small in size and overly London-centric, though 43% of the sample were clinicians working outside the capital, including in rural settings such as Somerset and Fife. It would have been preferable to have included more clinicians working in Community Teams as they are more likely to see women with BD without capacity issues but few responded to my invitation to take part so the sample was not as representative as hoped. The views of partners were reported by several of the women and by the specialist professionals but, considering the increasing likelihood that partners attend preconception counselling sessions, it is a limitation that partners' views on the process were not gathered directly.

#### **5.4.8 Implications for services**

The results of this comparative analysis highlight the need for a greater appreciation of the enormous importance women attach to motherhood. This has been noted elsewhere in studies focused on women with severe mental illness (Apfel and Handel 1993, Montgomery 2005) but in this study the professionals appeared not to appreciate how fundamental a factor in decision-making this was for women with BD. Both women and professionals called for improved training in perinatal mental health, which could also reduce stigmatizing attitudes towards mothers with mental health problems. In particular, postnatal training for midwives and health visitors should call attention to the need for sensitivity when caring for women who cannot breastfeed due to their health condition to avoid compounding their feelings of guilt and inadequacy. General psychiatrists said they would benefit from more knowledge on this speciality, and it would be helpful to provide them with additional sources of information and support in the Third Sector and elsewhere to which they could signpost patients. Women and both groups of professionals were in unison over the need to improve co-ordination between services so that psychiatric and maternity services had a better understanding of each other's roles and continuity of care could be improved. The need for careful planning over the perinatal period was recognized but this study highlights the need to include Advance Directives in such plans so that women with fluctuating capacity can feel more confident that their preferences will be taken into account should they become ill.

#### **5.4.9 Conclusion**

This comparative analysis of data gathered from women with BD and professionals involved in this study demonstrates the high degree of thematic overlap. The superordinate categories of Fear, Stigma, Contextual factors and Experience of services were represented in all three data sets, with the majority of sub-themes corresponding between the women and specialist groups. Most of the differences between the specialists' and generalists' approaches to the issues around pregnancy were a reflection of the different characteristics of the women they saw. Women who have

sought preconception advice and persevered to see a perinatal psychiatrist are very likely to be euthymic at the time. They are also more likely to be in a stable relationship, married or otherwise, and to be accompanied by their partner. Most general psychiatrists I interviewed saw very few women with their partners and/or completely euthymic. More typically they saw women for whom pregnancy was not an immediate issue. Also, because of the high threshold for access to secondary care, they were more likely to be treating women who had comorbidities and/or very severe illness, had little social support and were unstable or sometimes incapacitous. As a result, they were focused on the challenge of keeping their patients well and so were more concerned with how well-informed or otherwise they were on the subject of *avoiding* pregnancy. The rarity with which general psychiatrists saw women who were well and keen to talk about having a child was noteworthy. Like the perinatal specialists – but to an even greater degree – their encounters with women with BD were chiefly focused on how to manage risk.

## 6 Shared decision-making and Decision Aids

### 6.1 Introduction

This study has demonstrated the number and complexity of decisions which need to be considered by women with bipolar disorder in relation to pregnancy. Only approximately 50% of women in the UK live in an area served by a specialist perinatal team (Maternal Mental Health Alliance, 2018). In this thesis, many women who didn't have an opportunity to see a perinatal psychiatrist reported dissatisfaction with the amount and accuracy of the information they were given by GPs and general psychiatrists about pregnancy. Chapter 3 identified the problems women, their partners and families face when seeking reliable information and advice and Chapter 4 investigated the subject from the professionals' perspective. Decision-making in this area is highly individualized and so the main way of accessing such information is by consulting a medical professional who is able to discuss the available research evidence and explain how it relates to that individual woman's history and circumstances. So the *manner* in which these discussions are conducted, information is imparted and decisions are made is crucial to understanding how successfully or otherwise women's information needs are being met. Some felt they were denied access to valuable information, or that they were condescended to or discriminated against, particularly those who were unable to see a perinatal psychiatrist and so received advice from their general psychiatrist or GP. Some said they wished they had had access to a reliable source so they could feel more informed.

Even those women who were able to have a consultation with a specialist reported that they found it difficult to absorb all the statistics and research data relayed to them and would have welcomed an opportunity to prepare themselves more fully before the conversation with the clinician. When considering what might improve this situation in the pilot interviews, the idea of creating a Patient Decision Aid (PDA) was discussed and so the following questions on what interviewees thought of this idea were included in the topic guide for women (see Fig 3.1 and Appendices 3 and 4), and

in the post requesting input from members of the internet forum (Fig 3.2): “What sort of information do you think you need to know, and how do you think that would be best delivered? Would a decision aid be helpful? In what format?”

In view of the latest ruling of the Supreme Court on consent to medical treatment, *Montgomery v Lanarkshire Health Board* (Adshead et al., 2018), decisions *must* be arrived at after an informed dialogue between a clinician and his/her patient as a legal requirement. This reinforces the central importance of shared decision-making based on a meaningful discussion about the material risks and benefits of the available options (including the option of no treatment). I felt it was important in this thesis to explore the attitude to this process of both patients and clinicians and to provide a more detailed account of the operation of Shared Decision Making (SDM), especially in a mental health context, as background to that investigation. The data gathered from both women with BD and clinicians on this subject is presented and discussed together in this chapter but first the theory and practice of shared decision-making and the relatively recent growth in interest in decision aids to facilitate that process is described, followed by a discussion of whether such a tool would be useful in the context of pregnancy decision-making for women with BD, drawing on both evidence from the literature and data gathered in this study. Finally, I outline what such a decision aid might contain and what type of format might be the most practical and useful.

## **6.2 Background**

### **6.2.1 History of patient decision aids**

Patient decision aids have been used in healthcare since the 1980s, though initially their use was limited to physical health conditions (Simon et al., 2009). They can be in a variety of media (print, video or online) but increasingly they have an electronic format, with some incorporating an app and various interactive components (Agoritsas et al., 2015). They are used when there is more than one medically reasonable option



to diagnose or treat a health problem. At a minimum, a PDA describes the decision to be taken, the options available, and the outcomes of these options (including benefits, harms, and uncertainties) based on a careful review of the evidence. They are tools to help people participate in their health decisions in ways they prefer. PDAs go beyond simple provision of information, seeking also to help people think about their own values and how they influence the decisions they make. According to the International Patient Decision Aid Standards (IPDAS) Collaboration (summarised in Fig. 6.1 below, full document in Appendix 12), patient decision aids aim to do three things to prepare a person for decision-making: provide facts about a person's condition, the options and features; help people to clarify their values, and help people to share their values with their healthcare practitioner and others, so a course of action can be planned that matches their values.

**Figure. 6.1: IPDAS Checklist**

**International Patient Decision Aid Standards (IPDAS) Collaboration Checklist for Users**

- **Content: Does the PDA...**
  - Provide information about options in sufficient detail for decision making?
  - Present probabilities of outcomes in an unbiased and understandable way?
  - Include methods for clarifying and expressing patients' values?
  - Include structured guidance in deliberation and communication?
  
- **Development process: Does the PDA...**
  - Present information in a balanced manner?
  - Have a systematic development process?
  - Use up to date scientific evidence?
  - Disclose conflicts of interest?
  - Use plain language?
  
- **Effectiveness: Does the PDA ensure decision-making is informed and values based?**
  - Recognise a decision needs to be made?
  - Understand that values affect decision?
  - Discuss values with their practitioner?

Patient decision aids do not advise people on which course of action to choose, nor do they replace counselling from a healthcare provider. Instead they prepare people to discuss the options with their clinician. PDAs have developed as an adjunct to the theory and practice of medical decision making, which has three principle models: informed decision making, shared decision making and paternalistic decision making (Llewellyn-Thomas, 1995). 'Informed decision-making' denotes the model where the patient makes the decision autonomously based on information supplied by the physician. This contrasts starkly with the 'paternalistic model' which explicitly assumes a passive role for the patient who is regarded as dependent on the clinician as an expert (Parsons, 1964), a model which has lost favour in Westernised healthcare systems (Charles et al., 1999). 'Shared decision-making' (SDM), falls between these

two extremes and has been described as a two-way process where clinician and patient discuss available options and arrive at a joint decision (Charles et al., 1997). Perhaps the best definition comes from Elwyn and colleagues: “It is an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences” (Elwyn et al., 2010).

In addition to this model’s perceived ethical and democratic advantages (Charles et al., 1997), there is some evidence that SDM has a number of benefits, including improved patient satisfaction and health outcomes. For example, in a study of hypertensive patients, Schulman found that those who were actively engaged in their treatment also had better outcomes (1979). A review conducted by Marshall and colleagues also recorded greater patient satisfaction when using SDM and improved health outcomes (2005). However, the 137 studies included in this review focussing on chronic disease management were generally of poor quality. The authors also found great diversity in the interventions and outcome measures used. Furthermore, only 11% of included articles focused on mental health conditions and no subgroup analysis was conducted on them.

Some studies have found SDM to have an effect on treatment adherence, for example Wilson and colleagues found it had a significant effect on poorly controlled asthma (Wilson et al., 2010). However, a systematic review of the effects of SDM which included 11 RCTs (n=2,364) concluded that shared decision-making can be used effectively to reach agreement about long-term treatment decisions in patients with chronic conditions, but further research was required to determine its effect on adherence due to the limitations of the evidence (Joosten et al., 2008). A Cochrane Review on the use of aids in shared decision-making interventions (Stacey et al., 2014) which examined 115 studies involving 34,444 participants, concluded that there is high-quality evidence that decision aids compared to usual care improve people’s knowledge regarding options, and reduce their decisional conflict related to feeling uninformed and unclear about their personal values. They also cited further evidence that aids encourage more informed, values-based choices, and improve patient-practitioner communication.

### **6.2.2 International perspective**

Policies to promote shared decision making have been adopted internationally, with most progress in the United States, Canada and the UK (Elwyn et al., 2012). This is in part due to recognition of the ethical imperative to properly involve patients in decisions about their own care (Mulley, 2009, Edwards and Elwyn, 2009), and partly because of the accumulating evidence that the approach has potential benefits, including reducing costs (Légaré et al., 2014). Since 1995, when the Ottawa Health Decision Centre was established, Ottawa has been a centre of excellence in research on SDM and in developing decision aids for a number of conditions (Institute for Healthcare Improvement). In 1999, the Dartmouth-Hitchcock Medical Centre in New Hampshire, USA, set up a Shared Decision-Making Centre which has successfully disseminated thousands of tools in various formats to clinicians and patients and received positive feedback on their usefulness (Elwyn et al., 2010).

### **6.2.3 UK experience**

The United Kingdom has warmly embraced the theory of SDM. This was reflected in the government White Paper 'Equity and excellence: liberating the NHS' (Health, 2010) which states: "We want the principle of 'shared decision-making' to become the norm: no decision about me without me". The Coalition government declared that achieving world class healthcare outcomes could only be realised by 'involving patients fully in their own care, with decisions made in partnership with clinicians, rather than by clinicians alone'. In the UK's National Health Service, a small number of PDAs (for prostate cancer, osteoarthritis of the knee and breast cancer for example) have been piloted. However, it is now accepted practice that clinicians should implement the principles of SDM, as demonstrated in training protocols and treatment guidelines. For example, the NICE guideline on 'Patient experience in adult NHS services: improving the experience of care for people using adult NHS services' (2012) which was reviewed in August 2016, includes guidance to clinicians on shared decision making. The authors encourage clinicians to offer support to the patient when they are considering options, and explicitly state that they should "use the principles of shared decision making",

which are listed as: '1) ensure that the patient is aware of the options available and explain the risks, benefits and consequences of these; 2) check that the patient understands the information, and encourage the patient to clarify what is important to them, and check that their choice is consistent with this' (2012).

#### **6.2.4 Critique of Shared Decision-making**

Although the SDM model is now generally accepted as desirable and there is some evidence that it can reduce healthcare costs in the long-term (Oshima Lee and Emanuel, 2013), some clinicians and researchers have expressed misgivings about its application in practice. One issue is whether patients actually want to participate in medical decision making. Frosch and colleagues reviewed eight studies (ranging from 1980 to 1997) examining this question and found mixed results, with only 62.5% of the overall total number of patients surveyed saying they 'preferred participating in decisions' (Frosch and Kaplan, 1999). It was difficult to interrogate the reasons for this in the review, though some studies suggested desire to participate in decision-making may decline as a function of illness severity (Ende et al., 1990); others that patients preferred to comply with their clinician's orders in the hope of avoiding negative repercussions from hospital staff (Waterworth and Luker, 1990) and, more commonly, that a desire to participate in SDM was predicted by younger age and a higher level of education (Deber et al., 1996). It has been suggested that an over-emphasis on the benefits of SDM has led to under-recognition of the percentage of the population who prefer a 'passive' role, i.e. leaving the medical decision up to the clinician. In a secondary analysis of survey/interview based studies with a total of 2,754 Canadian outpatients, Deber and colleagues (Deber et al., 2007) found that 20.3% of patients with a current health condition preferred a passive role (as opposed to 77.8% preference for SDM and 1.2% for an autonomous role).

There are also some perceived problems with SDM from a clinician's perspective. Legare and colleagues (2008) conducted a systematic review of the barriers and facilitators to implementing SDM in clinical practice. Their review included 38 studies (in French or English worldwide) with data from a total of 3,624 participants (from 34

studies as four didn't report the number of participants). Time constraint was the most oft-cited barrier. Although there is a lack of robust evidence that SDM requires more time, clinicians in a variety of different cultural and organisational settings perceived it as a practical problem. Resistance from clinicians has been described as an important reason why SDM has not become more embedded in routine medical care in those countries where the concept has been embraced (Légaré et al., 2014). In a systematic review of the implementation of patient decision support interventions into routine clinical practice called "Many miles to go...", the authors identified significant challenges to implementation, including 'indifference' on the part of health professionals due largely to a perceived lack of confidence in the content of support interventions and concern about disruption to established workflows (Elwyn et al., 2013).

### **6.2.5 Development of patient decision aids**

The literature and research evidence on shared decision making has grown rapidly (Edwards and Elwyn, 2009) and there has been particular interest in developing aids to assist the process. For example, there are now hundreds of decision aids to help patients make medical decisions, as demonstrated by the latest iteration of a Cochrane Review on the subject referred to above (Stacey et al., 2014). The diversity of these instruments has led recently to the development of international standards (Elwyn et al., 2009). A total of 102 authors from ten countries collaborated over ten years to produce the International Patient Decision Aid Standards (IPDAS) (Elwyn et al., 2006). Agreed standards include the following requirements: a systematic development process; the provision of information (based on current evidence) about options and probabilities, presented in a balanced way; clarification of values; disclosure of conflicts of interest and the use of plain language. The IPDAS has produced a checklist (see Appendix 12) to guide the development of patient decision aids with three dimensions:

1) Content: whether the DA provides enough detailed information on the options; balanced and understandable presentation of outcome probabilities; methods for

clarifying and expressing patients' values and structured guidance on deliberation and communication

2) Development process: is the information presented in a balanced manner; has there been a systematic development process including peer review and field testing with users; is the scientific evidence up to date; are conflicts of interest disclosed; is it written in plain language (plus additional criteria if internet-based such as usability and security)

3) Effectiveness: Does the DA ensure decision-making is informed and values-based?

#### **6.2.6 Decisional conflict**

One way of measuring the effectiveness of a PDA is by calculating whether it has reduced users' decisional conflict. Decisional conflict is defined as an individual's perception of uncertainty about which course of action to take when choice among competing options involves risk, high stakes in terms of potential gains and losses, regret or challenge to personal values (LeBlanc et al., 2009, O'Connor et al., 2002). The main characteristic of decisional conflict as described by O'Connor and others is verbalised uncertainty. Other manifestations which may accompany it are: concern about undesired outcomes, wavering between choices, delaying decisions, questioning personal values, being preoccupied with the decision, and feeling emotionally distressed by the decision. According to O'Connor, decisional conflict arises from two sources. Firstly, people are uncertain because of the inherent difficulty of the choices they face, for example in the case of women with BD and pregnancy: whether they should risk harming the baby by taking a certain medication or not take it and risk becoming ill themselves (which might also harm the baby). The second source of decisional conflict concerns modifiable factors that make an inherently difficult decision more difficult. These include a lack of knowledge, unrealistic expectations, unclear values, social pressure, lack of support, lack of skills or self-confidence, and lack of resources. In the case of women with BD and pregnancy, sources of inner conflict are often accompanied by an acute sense of the guilt and regret they

anticipate feeling if they make the 'wrong' decision. It is possible to measure the degree to which a person's decisional conflict changes over the course of an intervention such as using a decision aid, and the Decisional Conflict Scale (DCS) has been developed and validated for this purpose (O'Connor, 1995).

### **6.2.7 Shared decision-making and decision aids in pregnancy**

The growing emphasis on patient involvement in decision-making, facilitated by the provision of comprehensive information, is particularly evident in the maternity care sector. Research has shown that most women wish to participate in decision-making. A survey of 1,336 new mothers in Australia found that over 96% had wanted to have an active say in decision-making during labour (Brown and Lumley, 1998).

In Scotland, a study of 301 pregnant women found that the vast majority wanted to either control decision-making (48%) or be involved (42%) (Hundley et al., 2001). A third study, of 12 maternity services in Wales, found that 90% of pregnant women and 83% of postnatal women preferred either to make final decisions themselves or to share the decision-making with care providers (O'Cathain et al., 2002). In the UK, this has been reflected in a series of government reports on the delivery of maternity services. In 1993 the *Changing Childbirth* report recognised the need for fully woman-centred maternity care (Group and Cumberlege, 1993), and subsequent documents such as *Better Births* have reinforced this objective (Births, 2016). NICE guidance on antenatal care for uncomplicated pregnancies states: "women should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals" (2008). However, in a Delphi study on shared decision making in maternity care, international experts were divided about the contribution of professional advice in SDM and about the partner's role (Nieuwenhuijze et al., 2014).

In the obstetric context, a number of decision aids have been produced. These mainly relate to specific issues such as the choice between watchful waiting and induction of labour (Berger et al., 2015) or the pros and cons of prenatal testing for Down's



syndrome (Nagle et al., 2008), but there have also been three systematic reviews looking at RCTs of decision aids in pregnancy (Say et al., 2011, Dugas et al., 2012, Vlemmix et al., 2013). These trials compared women receiving usual maternity care to those who used a decision aid, either prior to or during a clinical encounter, across a range of preference-sensitive decisions that pregnant women commonly face. The ten decision aids reviewed by these studies investigated a range of decisions: prenatal testing; method of pregnancy termination; management of breech presentation; mode of delivery following previous caesarean section and labour analgesia. All three reviews concluded that the use of decision aids conferred significant benefits, concluding that PDAs in pregnancy care significantly decreased decisional conflict, increased knowledge of care options and decreased anxiety. They also reduced decisional regret, reduced the proportion of women who were undecided and increased the accuracy of risk perception. However, all three of these reviews were limited by the heterogeneity among trials and the variability of tool types and health topics. Dugas identified a need to develop strategies to integrate pregnancy decision support systems within clinical practice in order to increase the likelihood that women's choices are supported (Dugas et al., 2012). More recently, Stevens and colleagues have discussed the benefits and barriers involved in using PDAs in routine maternity care (2016). Having reviewed the literature, they highlighted care providers' concerns about the limited usability of decision aids due to the characteristics of some women, for example low levels of education, poor computer literacy skills, and cultural barriers (Rees et al., 2009, Stapleton et al., 2002). Practical barriers to implementation included concerns about time pressures and additional costs.

### **6.2.8 Shared decision-making and decision aids in mental health**

Despite the development and proliferation of PDAs, most concern a patient's need to decide whether to have surgery or other invasive treatment, such as for spinal injury or various cancers (Wennberg et al., 2007). Only a small proportion relate to mental health (Drake and Deegan, 2009, Adams et al., 2007). Arguably, the need for shared decision-making supported by aids is even greater in the field of mental health where

the relationship between the patient and clinician is vital. In a speciality where patients can be forced to have treatment, empowering patients is an important counterbalance to clinician power. Under the medical paternalism model, the patient's voice was often effectively silenced and her opinion counted for either nothing or very little with the psychiatrist, who was the sole authority on what was best for her (Drake and Deegan, 2009). In order to recover and return to life as a functioning member of society, it is necessary to feel worthy of being heard – and listened to.

Shared decision-making is an alternative to what Drake calls “the wounding practice of medical paternalism” because it honours and values the voices of people with diagnoses, and recognises that there are two experts present in the medical consultation. Further, SDM enhances the working relationship needed to optimize long-term outcomes (Deegan and Drake, 2006) and is more likely to encourage a patient to trust her psychiatrist as it requires a demonstration of mutual respect and his consideration of her preferences and opinions. So if she subsequently becomes more ill and perhaps mildly paranoid or distrustful of authority, she is far more likely to accept advice from such a trusted source (on critical decisions such as the need to resume medication or go to hospital for example), than if she resents him for disregarding her views and dictating to her what she should do. This view is substantiated by a study conducted by Day and colleagues with 228 schizophrenic and schizo-affective UK inpatients (2005). They confirmed the importance of the therapeutic alliance with psychiatric clinicians demonstrated previously (McCabe and Priebe, 2004) and found that a positive relationship with the prescriber, involvement of the patient in treatment decisions, a medication regimen that minimizes adverse effects and a lack of coercion during admission were most likely to predict adherence to treatment.

Also, as with other long-term illnesses, encouraging people to be knowledgeable and take an active role in managing their own condition is critical (Mueser et al., 2002). As reported in Chapter 3, women sometimes felt thwarted in this aim and felt stigmatized and discriminated against, as has been reported by other people with severe mental illness (Hansson et al., 2013). This echoes other accounts of psychiatric patients describing their role in making decisions as largely passive (Goss et al., 2008, Beitingger

et al., 2014), whereas research has shown that the majority prefer to participate more fully in the decision making process (Dahlqvist & Jönsson, 2015, Hill and Laugharne, 2006, Adams et al., 2007). For example, when the European collaborative observational cohort study CEDAR (Clinical decision making and outcome in routine care for people with severe mental illness') asked nearly 600 outpatients with severe mental illness in six European countries (including the UK) whether they wanted to receive information on all aspects of their treatment (management, prognosis, alternative options for care), 80% said they did (Puschner et al., 2016). A systematic review including 65 studies on the information needs of psychiatric patients concluded that they wanted to be informed and involved in treatment decisions and greater efforts needed to be made to meet their needs (Paccaloni et al., 2004). Furthermore there is tentative evidence to suggest such involvement can aid the recovery process. Another paper from the CEDAR group concluded that there was an association between level of involvement in decision-making and subsequent recovery, though the authors called for more longitudinal research to understand the direction of any causal relationship (Loos et al., 2017).

### **6.2.9 The particular usefulness of SDM and decision aids in mental health**

Other studies have demonstrated that shared decision-making enhances the relationship between clinician and patient and encourages the latter to take more responsibility for managing their mental health and adhering to agreed programmes of treatment which might lead to better long-term outcomes (Van Os et al., 2004, Deegan and Drake, 2006). Whether or not to use medication that has been prescribed is a dilemma which confronts most people with a long-term psychiatric condition like bipolar disorder. For many psychiatric medications, how they work is uncertain and their likely effectiveness for a particular individual is unpredictable. The distress caused by adverse side effects such as significant weight gain or sexual dysfunction is often under-estimated by psychiatrists (Mitchell and Selmes, 2007), and the question of adherence is further complicated by issues of personal identity and quality of life (for

instance many people refuse to take lithium because of what they perceive to be its 'stigmatizing' associations). So many studies have looked at how shared decision-making might improve treatment adherence in people with severe mental illness (Mitchell and Selmes, 2007, Wilson et al., 2010, Joosten et al., 2008).

#### **6.2.10 Facilitators and barriers to SDM in mental health**

In a qualitative study looking at the factors influencing psychiatric patients' involvement in shared decision-making, Matthias and colleagues found that these included: the patient/provider relationship, fear of being judged and perceived inadequacy (Matthias et al., 2014). A systematic review of patient-reported barriers and facilitators to SDM concluded that individual capacity to participate in SDM depends upon two key factors: knowledge and power (Elwyn et al., 2013). Shared decision-making provides a framework which encourages patient participation, thus building a patient's confidence and self-respect. It has the potential to restructure the relationship between clinician and patient and encourage a joint sense of working together to arrive at a shared decision (Deegan and Drake, 2006). However, it is still not widely implemented (Beitinger et al., 2014) and identified barriers to its use in mental healthcare settings include not only practical considerations such as time constraints but also clinicians' fear of using SDM in critical situations where patients might lack insight and put themselves in danger (Hamann and Heres, 2014, Drake and Deegan, 2009). A German study investigating the extent to which psychiatrists adopt the model in their treatment of patients with schizophrenia found that (in a sample of 352) 44% of psychiatrists reported that they most frequently applied a paternalistic decision-making style, 51% most frequently applied shared decision-making, and 5% said they most frequently applied informed choice (Hamann et al., 2009). Choice was largely determined by their appraisal of a patient's decisional capacity.

#### **6.2.11 Lack of research on mental health decision aids**

Research on shared decision-making in mental health is still in its infancy, as

demonstrated by a Cochrane Review of ‘Shared decision-making interventions for people with mental health conditions’, conducted in 2010 (Duncan et al., 2010). Authors Duncan and Hagen found only two studies worthy of inclusion, both German. One study was conducted with inpatients with schizophrenia and the other with people newly diagnosed with depression in primary care. It stated that no firm conclusions could be drawn about the effects of shared decision-making interventions for people with mental health conditions: and that there was “an urgent need for further research in this area”. The 2010 review has not been updated as little more research has been done specifically on SDM interventions in mental health, though Hamann and colleagues have published a protocol for a trial of an enhanced version of shared decision-making called SDM-PLUS designed to address some of the difficulties of using the model with severely mentally ill patients in inpatient settings (Hamann et al., 2017). There is also a decision aid for decision-making about antidepressants in pregnancy which has been trialled in Canada and the UK (described below at 5.2.13). Duncan and Hagen’s call for more research on aids to mental health decision-making has been echoed by others, notably Elwyn (2010).

### **6.2.12 SDM and decision aids in bipolar disorder**

The efficacy of shared decision-making specifically for people with bipolar disorder has not been studied, although Zeber and colleagues (2008) have examined the effect of the therapeutic relationship on treatment adherence in BD in a sample of 435 US veterans (14% women). They concluded that patient perceptions of the therapeutic alliance were highly associated with medication adherence. Also, a systematic review of studies examining communication and decision-making in mental health focused on bipolar disorder has been conducted (Fisher et al., 2016). Described in Chapter 1, this review included only two studies with exclusively BD samples (Sajatovic et al., 2005, Sylvia et al., 2013), both addressing the association between therapeutic relationship and treatment adherence. In the former qualitative study, individuals with BD (n=52) specifically identified and placed value on the collaborative practice model (in which patients are active managers of their illness within a supportive social environment).

This preference was also reflected in Fisher's later study (part of the Systematic Treatment Enhancement Programme for Bipolar Disorder or Step-BD project in the U.S.) where 3,337 participants (65% with Bipolar I disorder) were assessed with a battery of measures including the Care Satisfaction Questionnaire. Researchers found that patients' perception of collaboration on the part of their psychiatrist was positively associated with medication adherence. Fisher and colleagues found a mismatch between the majority of patients' desire to be fully involved in decisions about their treatment and the actual level of involvement reported (with qualitative studies revealing that the involvement level varied according to their current BD symptoms and disability (Sajatovic et al., 2005, Bilderbeck et al., 2014)).

People with BD might be expected to differ from others with mental illness (e.g. schizophrenia) in terms of their preferences and experience of involvement in treatment decision-making, given the fluctuating nature of BD symptoms and associated disability interspersed with periods of wellness (Tlach et al., 2015). Fisher et al.'s review (2016) highlighted that patients with BD tend to prefer an active-collaborative decision-making role, and desire greater levels of involvement than they are currently experiencing. As this patient group has been largely neglected in the literature compared to schizophrenia and depression, they called for more research to delineate the specific involvement preferences of BD patients, and cited PDAs as a potentially useful means of increasing patient involvement and promoting more informed, value-based decision-making. The first computerised decision aid for people with BD designed to help with long-term decisions on medication has been developed recently in Norway and is currently being trialled (Eiring et al., 2017).

### **6.2.13 Decision aids in perinatal mental health**

In the specific area of pregnancy decision-making for psychiatric patients, there has been little research. This is despite the fact that decision aids are considered particularly useful in 'preference sensitive' decisions (where the decision relies heavily on the personal attitudes of the decision-maker and/or there is an insufficient or conflicting evidence base) (Barratt, 2008). This obviously applies to the area of

psychotropic medication in pregnancy which women often choose to stop taking for fear of harming the fetus. For example, a multinational web-based study found that approximately one in two pregnant women using psychotropic medication demonstrated low adherence in pregnancy (Lupattelli et al., 2015). An advantage of the SDM model over the autonomous 'informed decision-making' model in the perinatal context is that it has the potential to mitigate a pregnant woman's feelings of guilt if the baby is born with some defect which could be attributed to the medication she chose to take. Such feelings could be corrosive and have an extremely detrimental effect on her mental health if she feels that she alone bears total responsibility for the decision to continue medication. If she feels responsibility for the decision has been 'shared', she is less likely to suffer guilt to the same degree. Alternatively, if she was 'told' to take the medication by her clinician in a paternalistic way and the baby is born with a defect, she might blame him or her, potentially ruining their therapeutic relationship (and perhaps provoking a legal claim).

An online PDA has been developed in Canada to help women make choices about taking antidepressants in pregnancy (Vigod et al., 2019) and a pilot RCT has demonstrated that it is acceptable to women and reduces decisional conflict more than clinical care alone in a non-specialist setting. In the UK, mental health clinicians can consult NICE guideline 192: 'Antenatal and postnatal mental health: clinical guidance and service guidance' to help them navigate the difficult terrain of advising a woman with mental illness on treatment decisions (NICE 2014). The section on advice and monitoring for women with mental health problems who are planning a pregnancy, pregnant or in the postnatal period lists the main areas that mental health professionals should discuss with their patients:

- the uncertainty about the benefits, risks and harms of treatments for mental health problems in pregnancy and the postnatal period
- the likely benefits of each treatment, taking into account the severity of the mental health problem
- the woman's response to any previous treatment
- the background risk of harm to the woman and the foetus or baby associated with the mental health problem and the risk to mental health and parenting

associated with no treatment

- the possibility of the sudden onset of symptoms of mental health problems in pregnancy and the postnatal period, particularly in the first few weeks after childbirth (for example, in bipolar disorder)
- the risks or harms to the woman and the foetus or baby associated with each treatment option
- the need for prompt treatment because of the potential effect of an untreated mental health problem on the foetus or baby
- the risk or harms to the woman and the foetus or baby associated with stopping or changing a treatment.

This list gives some idea of the complex nature of the decisions to be made. The previous iteration of the guideline in 2007 recommended that decision aids for helping pregnant and breastfeeding women with mental disorders to make informed decisions about their care should be designed and trialled (NICE, 2007). This chapter examines what women with BD and the health professionals who help them think about that idea.



## **6.3 Qualitative exploration of views on the usefulness or otherwise of a decision aid for women with BD considering pregnancy among women, perinatal specialists and general psychiatrists**

### **6.3.1 Methods**

The methodology employed with the three sample populations (a) women with BD; b) perinatal health professionals and c) general adult psychiatrists has been described in detail in chapters 3 and 4. Qualitative methods were used for all participant groups.

For a) data was extracted from 21 semi-structured interviews with women with BD considering pregnancy, pregnant or recently pregnant, together with written responses on an internet forum for people with BD (See 3.2 for details).

For strand b) data was analysed from a focus group of specialist perinatal health professionals, comprising 5 perinatal psychiatrists, an obstetrician, a midwife, 2 psychologists, a Health Visitor and community mental health nurse; all of whom had perinatal experience (4.1.1).

For c) data was analysed from semi-structured interviews conducted via telephone with an opportunity sample of general adult psychiatrists (4.1.2).

### **6.3.2 Results**

Data in this chapter relates to women's and clinicians' experiences of decision making and their opinions of the usefulness or otherwise of a decision aid in this context, so Women's views, Specialist perinatal mental health professionals' views and General adult psychiatrists' views will be reported separately and discussed together. Views were also collected on what might be the most useful format were such a tool to be developed, and what were the main barriers and facilitators to shared decision making.

### 6.3.3 Women's views

#### 6.3.3.1 Barriers to Shared Decision Making

As reported in Chapter 3, women with BD who gave their views on pregnancy decision making in this study reported experiencing significant barriers to shared decision making with their clinicians. These fell into two main categories:

##### 6.3.3.1.1 Clinicians' lack of knowledge

A lack of knowledge of the research and treatment alternatives in the perinatal period on behalf of GPs and many general psychiatrists; for example,

*'Well [sigh] I think a lot of [the psychiatrist's] attitude is to do with a lack of knowledge. And almost a fear of being found out that you don't know much about perinatal stuff... So for example, ...I distinctly had this impression that if you were on Lithium you would basically end up with an unviable foetus who was so badly deformed, just like Thalidomide but worse, you know? ...But when I went to see [the perinatal psychiatrist] and she told me actually what the risk is ... I just thought 'Gosh this risk is on a completely different scale from what I've been led to believe'. P3.*

This perception that professionals were avoiding discussing the matter because of their own lack of knowledge and/or discouraging women from pursuing the idea of getting pregnant in order to avoid something that might prove difficult for them to manage was also referred to by participant 10. She said she stopped asking for information "because I'd been so put off by the psychiatrist", and there were more examples of similar treatment:

*'It took us quite a long time to become proactive ...I think it would have been good...to have some hard facts from them ...rather than... just sort of putting me off really.' P7*

#### **6.3.3.1.2 Stigma and discrimination**

Stigmatizing attitudes of professionals towards women with mental illness having children were referred to as inhibiting involvement in a collaborative decision-making process. Women often reported being met with discouragement, or even disapproval, from their GP or general psychiatrist when they approached them to say they wanted to have a child. As participant 3 said:

*'We ...were made to feel that we were being irresponsible in thinking about [having a baby] and that it would all end badly basically. I got a lot of negative information ...along the lines of ...  
'Well you know, that's such a big complicated decision, you couldn't possibly think about making that decision, you know, until you're totally better' and things like that ...It made me very frustrated and quite angry'.*

Answering the question "What was the attitude of health professionals when you raised the possibility of having children?", a woman on the e-forum replied:

*'When mentioned to my GP her attitude was one of I cannot have any more children as I would not be able to cope with having bipolar disorder as well. I did not find this helpful because I feel as though people with bipolar disorder deserve to live as normal a life as everyone else and we all deserve to achieve our hopes and dreams including that of having children'.*

#### **6.3.3.2 Practical obstacles to SDM**

Some women felt they didn't have enough time to discuss such a complex matter with their doctor. Participant 15 said she would be grateful to be signposted to web-based information in a decision aid

*'that you can go and explore off your own back because I don't suppose GPs or psychiatrists would even have the time to help you go through that'.*

### 6.3.3.3 Shared Decision-making Facilitators

A major facilitator of meaningful shared decision-making in this context was the opportunity to consult a specialist perinatal psychiatrist who would have a better grasp of the research in this area, and be experienced in advising on the risks and benefits of different medications and treatment options. As discussed earlier, only about 50% of women in the UK have access to such a service, and there are numerous examples in this study of those women who had been referred to a specialist expressing the view that they had benefitted from it (see Chapter 3). For example, one interviewee described the advantages of seeing a perinatal psychiatrist:

*'It was very helpful, talking about the percentage risks and the risks at different periods ...you just couldn't get that information from anyone else.'* P12

### 6.3.3.4 Women's views on the usefulness of a Decision Aid

Towards the end of interviews, I asked women what they thought might help with the decision-making process. Some responded spontaneously with, for example, the suggestion of user-friendly information. If they didn't respond initially, I prompted by suggesting the creation of some type of decision aid and followed up to ask what format – paper, electronic or other – they thought would be most useful. Sometimes there followed a discussion of whether the tool should be interactive or not, though the question on the e-forum was:

*"If we could produce a 'decision aid' of information and advice to help with this decision-making process, what do you think would be the best format: a leaflet, an interactive module on the website, an app for mobile phones - or something else?"*

When discussing what might have improved the decision-making process and whether a PDA of some sort might be useful, the overwhelming consensus among those who expressed an opinion was positive. As this woman on the e-forum said:

*'I have just given birth to my [baby] 10 weeks ago. I have bipolar 1 and had a bad experience from start to finish. I think an app and leaflet would be a great idea to help others go through pregnancy easier'.*

Several women agreed that something interactive would be helpful, and that efforts should be made to make women aware of it:

*'For me a decision aid would be best as something to access through the website. Perhaps made available through different websites dealing with mental health. But it should be prominent so I know of its existence when I need it.'* (e-forum)

One interviewee emphasized that the information needed to be delivered in a comprehensible, jargon-free way, and with a compassionate understanding of the potential it had for provoking greater anxiety in the recipients, who were understandably hoping that they would have a relatively 'normal' pregnancy and birth.

*'[The Decision Aid shouldn't be] forbiddingly medical, but kind of quite engaging and take account of people's hopes and expectations around having a baby and ...friendly not ...just 'doomy and gloomy''. P13*

#### **6.3.3.5 Views on the best format for a decision aid**

A correspondent on the e-forum thought a paper version would be best:

*'I think if a decision aid of information were to be produced and done in one format only it would be best as a leaflet so it's accessible to all, including the less technical.'*

Younger women generally preferred an aid having an electronic format of some kind:

*'I'd prefer it in a website ...I can look at that in my own time and it's just a lot easier to access.'* P18 [late 20s]

*'An interactive module would be nice. Mobile phone app is better but may be too much for just one decision, as I won't keep it on my phone after I've made my decision.'* (e-forum)

Several favoured a combination of formats:

*"I think paper's always good and it's far easier to give a woman something to take away for her to read through and consider. However, it's not the most imaginative tool and ...it can't be*

*individualized, so ...I think perhaps some web-based tool or a combination'. P10*

*'I think some kind of guide or booklet for women ...something that's longer length would be invaluable. ...Or something interactive maybe would be useful as a resource, and case histories are always interesting'. P13*

An interviewee (aged 34) expecting her third child agreed:

*'We don't have this information while we are pregnant ...they don't tell us about these things. I think they should have more leaflets...and maybe ...for the pregnant woman to ...see videos ...is good. Maybe videos of the place where mothers and babies go [an MBU], and some of the mothers after having baby...who have suffered ... but who recover.' P8*

Responding to the e-forum question "what would be the best format for a decision aid: a leaflet, an interactive module on a website, an app for mobile 'phones or something else" this woman said:

*'I think all of them are great ideas. I think leaflets in doctor's, midwife offices, scan departments where people can just pick them up would be great. For people that use this website [Bipolar UK] an interactive module would be good and I would definitely use it. If advertised well enough an app would help to reach people that may not use this website.'*

#### **6.3.3.6 Need for decision aid to be underpinned by high quality research**

A related theme linked to the usefulness of a PDA in this area which was frequently highlighted in women's responses was the need for higher quality research to back up the information provided by the tool. As this woman on the e-forum commented:

*'There is a massive gap in knowledge. I have looked into the medications I am on and ... there really are not a lot of studies done on this matter and therefore women like me cannot make an informed decision before becoming pregnant'.*

Also on the e-forum, a woman who said she was 24 years old expressed herself forcefully:

*'There definitely needs to be more research done on medication use during pregnancy, as having the choice between potentially harming your child through medication or potentially harming yourself/your child through your illness is not really much of a choice. I know it's ostensibly not allowed for ethical reasons, but they've done plenty of tests on what medications are safe for physical health problems during pregnancy, so I believe it's actually more to do with medical professionals dancing around mental health problems (as usual).'*

Another woman on the e-forum, who said she was formerly a student midwife, agreed:

*'Because of my background I feel very well-informed but what I need to know about is the effects and outcomes of medications - and research is lacking, I know ethics limits research in this area but there needs to be more research. Reading about the odd case that had a good pregnancy outcome on x,y,z medication is only helpful to a certain extent, what happens to these babies as they grow up and into adults?'*

### **6.3.4 The views of specialist perinatal health professionals**

#### **6.3.4.1 Views on SDM**

The health professionals taking part in a focus group (see Chapter 4) had been trained in perinatal mental health and were experienced in discussing issues relevant to women with bipolar disorder. They all concurred that they adopted a 'shared decision- making' style in consultations, as this perinatal psychiatrist explained:

*'I am usually very clear (I hope) that it's the woman's decision and I am there to help provide information and think through the issues, and I think most women seem happy with this'.*

At the end of the session, the group discussed the merits and disadvantages of developing a Decision Aid to help women with BD make decisions around pregnancy. The themes that emerged were: *Complexity; A Good Idea; Shared Experience* and

Format.

#### **6.3.4.2 Complexity**

The perinatal psychiatrist opening the discussion was uncertain:

*'I think it's so complex and difficult that I wonder whether something can capture the complexity of making these difficult decisions or should it be something that provides information in accessible and easy ways so it can be used with a woman? So it depends what you mean by decision aid really. What I can't see working is something that you just point somebody towards, they put the information in and say that's the medication for you and you're not to bottle-feed or whatever. But for me it's something about something that can be used together [with the clinician] and I can see something about that that's valid'.*

#### **6.3.4.3 A Good Idea**

Most of the group were broadly in favour, for example another perinatal psychiatrist said:

*'I can see it could be helpful as part of the discussion that you have with the women to help facilitate the discussion and also for her to take home and use to help her have that ongoing discussion with other family members.'*

Another perinatal psychiatrist said: *"I think it would be a fantastic tool to have'.*

It was suggested that that real-life examples of how women had approached this type of decision-making might be helpful:

*'I can see some kind of aid to help decision-making in terms of maybe ... [in addition to] all the information and the evidence ...also maybe case studies for if women don't know other women or aren't prepared to go to meet other users (because often they may not have the time or resources to do that), but some illustrated examples talking through the various scenarios might help.'*

A community psychiatric nurse who worked in an area without a perinatal service approved of the idea:



*'In my experience, women are keen to make the "right decision" and are worried about anything which could harm their baby. They very much want professional help in guiding them through the decisions. It is difficult to get all the professionals in the room who would need to be involved to fully make the decisions, so perhaps a decision aid could involve collecting info from different professionals.'*

However, the midwife in the group disagreed initially that an aid might be useful or feasible:

*'I think it would be impossible really wouldn't it? And I think ...no one could have the strength or decision-making capacity [to deal with] something like that on their own.'*

#### **6.3.4.4 Shared Experience**

But when it was suggested that such an aid would not be used by a woman in isolation but as a prompt or facilitator for a discussion with health professionals, she agreed that it could be useful, and an improvement on internet searching:

*'It's more about ...good, clear information, because going on the web is just the worst thing in the world because there's so much out there that scares you to death that I think to have something really clear like that would be alright.'*

A perinatal psychiatrist with over ten years of experience advising women on this issue was enthusiastic about a decision aid's usefulness:

*'Women could also share this with partners and others if they want to. I don't see why it would do more harm than good if it's clear that it's about helping to weigh up complex issues rather than providing an absolute right answer.'*

#### **6.3.4.5 Format**

Summing up the pros and cons, the group were generally positive about the possibilities of an online tool, envisaging it as something to give women access to before and after an initial face to face discussion with a specialist. A perinatal psychiatrist suggested that, if it were done well, it could also be made available as a

resource on the Bipolar charity's website to help women who don't have access to perinatal psychiatrists.

*'What I think we [are saying] in the group is that we need to be realistic and we're not going to have something that has lots of tick boxes and comes out with a "right answer". Being able to have layers of increasingly complex information (depending on what women want) and being able to highlight all the issues women need to consider could be really helpful I think.'*

### **6.3.5 Views of general psychiatrists**

The 14 general adult psychiatrists interviewed (see section 4.1.2.1 for methodology) were asked if they had any views on the development of a PDA for this area of healthcare and similar themes emerged: A good idea; Individualisation; Shared experience; Capacity and Format.

#### **6.3.5.1 PDA for BD and pregnancy: a good idea or not?**

When asked what they thought about developing a decision aid, general psychiatrists made a number of comments on its likely usability and potential shortcomings, but they were unanimous in their approval of the general idea, describing it as "a really good idea" (P9); "it would be enormously helpful"; "that would be awesome" (P10) and "excellent" (P14). Participant 14 thought it "would be excellent for people to see what is available and learn a bit about risks and treatment [options]". Some saw it as a useful prompt:

*'that will stimulate further questions and maybe prompt the patient - and in turn the psychiatrist - to raise certain issues ...it might prompt the psychiatrist to think about things that they wouldn't have otherwise thought about. So, yes I would endorse that. I think it would be really good.'* (P5)

Some suggested it might also help to record the course of the pregnancy and involve

partners more:

*'It can only be a good thing to encourage women and their partners, (or whoever is involved in their care) to make regular records of their mental well-being and treatment etc.'* (P14); and

*'It would also be very useful for the partner, especially if he hasn't seen his wife or girlfriend very ill so doesn't really have any framework to work with'* (P7).

#### **6.3.5.2 Individualization**

Though keen on the PDA as a source of information – “the more information you can give people the better” (P7) – and general aid to the decision-making process, many interviewees were concerned that it might over-simplify what is a very complex and individual decision.

*'I think it's a good idea in principle. I think it would have to be very carefully thought through because it is so individual isn't it? ...Put it this way, I'm glad it wouldn't be me having to try and design that. I think it would be a real challenge to be able to break down the complexities of each person's circumstances.'* (P7)

Participant 14 agreed and described a recent experience where his client had wanted

*"a very concrete answer as to whether to take medication in pregnancy, which is not always possible to give, and so I think it needs to be clear that this app will not necessarily provide that".*

#### **6.3.5.3 A shared experience**

Because of the unique complexity of each individual woman's family, mental health and medication history, let alone her social circumstances and general health approaching pregnancy, most psychiatrists thought it would be better to use the PDA in consultation with their patients, rather than as a stand-alone tool.

*'It would be really good to do that together with the patient wouldn't it? Rather than in isolation. I think you probably need to have more of a shared exploration rather than "You go off ...and go through it and then we'll discuss it afterwards." I think that would, I*

*suspect, probably engender quite a lot of anxiety so then you're trying to self-manage the anxiety rather than going through it bit by bit with the woman, and just having a slightly more grounded discussion.'* (P13)

*'I suppose what I would worry about is if you have this sort of decision aid online that gets to the end and someone comes out of it thinking, "Well, you know, I absolutely should not stay on what I'm on or it's absolutely now my fault if something happens because I've chosen to say on medication," when actually the decision is often more complex than that.'* (P7)

Participant 6 agreed that users of the aid should be made very aware of its limitations, but thought it would be acceptable for a woman to go through the PDA as a preparation for a consultation:

*'I suppose I'm a little bit wary about it ...because everyone's experience of bipolar disorder is different, and the risks and benefits for that individual, how ill they've got when they've got ill and what have you, that really needs a conversation I think. So I don't think [a decision aid] could replace that really. [If as a precursor to having that conversation] that sounds good.'*

Two interviewees thought it would be a good idea for GPs to be aware of the resource so they could explain its use as a preparation for a referral to secondary care.

*'If the GP is able to give someone that kind of information or links to something like that, so that someone isn't coming to me and then I'm just hitting them with all this information; they've actually had time to think about it, to process it, to start that decision making process before they've even come to see me ... sometimes you do get the situation where you're meeting someone for the first time and they've got this really big decision and you're hitting them with all of these statistics and all this information but they're then expected to take that all on board within an hour on the first clinic meeting – that can be quite difficult. I think the more information someone has before you have that conversation would definitely be a big advantage.'* (P7)

Participant 3 suggested that, as well as GPs, midwives and obstetricians “might find it kind of handy perhaps too?” (P4). Some thought it would a good way to use the consultation time more constructively:

*'I think that would be wonderful because you find in these consultations you've got so much to cover you can often become a bit unstructured, and actually to have something that a) they own rather than you doing it to them, I think that would be wonderful, yes. And it would just make my interview a lot easier as it's like - this is where we're going; have I remembered all that?' (P10)*

#### **6.3.5.4 Capacity**

Some interviewees, (in particular those who worked in acute settings, either on high dependency wards or in outreach services), were more doubtful about their patients' capacity to make use of a decision aid (see above). They expressed concerns that women with very severe illness, high levels of medication use and often comorbidities and substance abuse problems too, may find using such an aid too challenging, and lack confidence with technology. As participant 3, who ran an assertive outreach team and high dependency unit, said:

*'This app sounds very good but would probably be most useful for those patients who are fairly high functioning. I am not sure that my patients in AOT (Assertive Outreach) would be confident using it.'*

Participant 10 pointed out that people with very severe psychotic illnesses would be "significantly disadvantaged from accessing or using online tools because they don't have smartphones ...so couldn't use an app."

#### **6.3.5.5 Format**

When asked what would be the best format for a DA, the overall consensus was in favour of something electronic, either web-based or on an app, or both, preferably with downloadable components:

*'I think these days a decent website that's looked after [and] curated and from which you can download things like pamphlets, leaflets, is probably preferable. Because paper things when they're printed often got lost and out of date, or they don't get restocked, whereas a website that has its own domain and is easy to access and you think of it as the central place for all this information would be really good. A validated source.'* (P5)

*'[A decision aid app] is a good idea. Patients seem to like apps and if it's something that they can come back to and have a think about, and yes it's maybe more accessible than a leaflet'. (P4)*

*'These days I think an online tool is probably the best way to go. Something with nice graphics and you click on and it takes you in to the next bit and all that.' (P6)*

Some favoured apps, others a website with downloadable leaflets that could be printed.

*'I would say something online because of the accessibility but something that you could go and print off if you wanted.' (P9)*

*Few were concerned that their patients wouldn't - or couldn't - use a technological aid: "I think a downloadable PDF on a website would be good as most patients seem to have phones and seem reasonably 'tech savvy'" (P11).*

*'Apps are quite good because people carry their phones around with them everywhere so that sort of ready accessibility is something that they can look at again and again' (P13).*

One psychiatrist raised the issue with an electronic aid of the need for good access to the internet:

*'I carry my laptop round with me in consultations now so that I can actually go online with patients because you can't rely on our hospital computers ... they will take twenty minutes to load up ...it's a nightmare. So I think having two options [computerized and paper] would be great.'*

Another concern was security:

*'You would need to think carefully about how to ensure security (encryption etc.) given the personal and medical info that would be recorded.' (P14)*

## 6.4 Discussion

In recent times, a great deal more attention has been paid to the importance of the therapeutic relationship between patient and healthcare provider and the need for the former to play a full part in decisions made about their healthcare. In no arena is this more relevant than mental health (Berk et al., 2004). Moving away from a paternalistic model and improving two-way communication could have many positive benefits including increases in patient knowledge, adherence, health outcomes and satisfaction (Stevenson et al., 2004). Involvement in decision-making is particularly important in bipolar disorder, as patients are responsible for actively self-managing their illness to prevent further relapse (Malhi et al., 2014, Deegan and Drake, 2006).

Shared decision-making (SDM) has been widely accepted by clinicians and policymakers alike as providing the best model to achieve “informed preferences” by sharing the best available evidence and supporting service users to consider their options (Elwyn et al., 2010). Some would consider such decisions in perinatal mental health to be even more weighty as they concern the future health and wellbeing of a woman’s child as well as her own. However, there has been minimal research in this area. American researchers have produced a conceptual model for psychiatrists treating women with major depression (MDD) during pregnancy (Wisner et al., 2000). More recently, a survey of 100 pregnant or postpartum women with major depressive disorder found that most preferred an active collaborative role in treatment decision-making (Patel and Wisner, 2011). They concluded that engaging women in these discussions, though difficult, may lead to improved communication, decision-making and quality of care.

There has been some work on the treatment preferences of women with perinatal depression (Goodman, 2009, Jesse et al., 2008), and, as mentioned, a decision aid to help women make choices about anti-depressant medication in pregnancy has been developed (Vigod et al., 2019) but there has been no research into the specific needs of women with BD faced with making treatment decisions regarding pregnancy. And as bipolar disorder carries the greatest risk of a severe episode of illness being triggered by pregnancy or childbirth, women with this condition are in particular need of access

to the highest quality information and research available, together with assistance to understand it and apply it to their unique circumstances.

Despite SDM now being considered the most acceptable model for the conduct of consultations between medical practitioners and their patients, many women in this study stated that it still wasn't happening universally, in line with the results of Fisher et al.'s review (2016), and they reported a number of barriers to its effective implementation, as has been reported elsewhere (Megnin-Viggars et al., 2015). Studies with psychiatric populations have demonstrated that psychiatrists score poorly on measures of patient involvement (though female and/or younger doctors score higher) (Goossensen et al., 2007). Women spoke of their psychiatrists giving them no information, of 'fobbing them off' or sometimes giving them inaccurate information. This reflects the experience of women with BD in the US who attended a specialist pre-pregnancy psychiatric consultation (Viguera et al., 2002), in which 45% of the respondents (29 of 65) had been advised not to become pregnant by a health professional. Several participants in the current study recognized that ignorance on behalf of health professionals was a significant problem: perinatal psychiatry is a specialty and many GPs and psychiatrists understandably have less expertise in this area (Heron et al., 2012b, Shakespeare et al., 2006), a reality acknowledged by general psychiatrists interviewed in this study (chapter 4). However, the fact that in approximately half of the UK specialist care didn't exist when this study was conducted (MMHA, 2015) highlighted a yawning gap in provision for these women and their families (Khan, 2015).

#### **6.4.1 Stigma: a barrier to shared decision-making**

Many women in this study felt disempowered by their lack of knowledge which in turn hampered their ability (and that of their partner) to fully engage in shared decision making with their clinician. To some extent, this is likely to reflect the unequal power dynamic between physician and patient in psychiatry referred to above and, in the current context, the persistence of stigmatising and disparaging attitudes from professionals towards women with BD considering motherhood in particular, as



reported elsewhere (Clement et al., 2015, Dolman et al., 2013, Diaz-Caneja and Johnson, 2004). However, such attitudes were not exhibited by the perinatal mental health specialists in this study, perhaps reflecting the additional training and specific experience of this group. Notably, the general adult psychiatrists interviewed also did not exhibit stigmatizing attitudes to women with BD enquiring about motherhood. Perhaps some of this mismatch with the women's data can be explained by the relatively young demographic of the sample: the average age of interviewees was 35 (30 to 46), 8 male, 6 female, and the majority were young enough to have received some perinatal component in their psychiatric training.

#### **6.4.2 Potential usefulness of a Decision Aid**

In the current study, all women who responded to the question welcomed the idea of a decision aid to help them and their partners weigh the risks versus benefits of different treatment options when discussing them with professionals. Providing women with a well-designed decision aid containing good quality information could allow them time to think through the complex issues facing them before attending a consultation. This could be empowering and increase women's self-confidence to engage more fully and 'share' in decision making with her clinician, thus improving the quality of the therapeutic relationship. This in turn might have a positive effect on adherence (Zeber et al., 2008, Sajatovic et al., 2005) and treatment options (Gaudiano and Miller, 2006). Furthermore, the health professionals who considered the idea were also generally in favour, once it had been established that such an aid would be used as an adjunct to a consultation with a professional, rather than as a stand-alone tool. This concurs with previous research demonstrating that when psychiatric patients who received a treatment information sheet were able to discuss it with a healthcare professional they exhibited a significant increase in knowledge about medication, whereas receiving a fact sheet alone had no significant effect (Evans et al., 1996). General adult psychiatrists interviewed were also very keen that the decision aid should form part of the consultation process, with some in favour of encouraging women and their partners to use it in preparation for their meeting with the

psychiatrist. However, others expressed concerns that this might engender anxiety in some patients and might even cause a pregnant woman to become alarmed enough about the possible teratogenic effects of the medication they were on to suddenly stop taking it. Perhaps the likelihood of this happening could be investigated at the piloting stage. It might also be mitigated by a carefully worded introduction emphasising the need to delay any decision until it could be shared with a clinician.

If a patient decision aid (PDA) for bipolar and pregnancy were to be developed, it might be useful to study whether it had a significant effect on women's 'decisional conflict' (5.2.5 above) by incorporating the Decisional Conflict Scale (DCS) to assess whether use of the PDA had affected a user's uncertainty over a decision (Vigod et al., 2016). The DCS has been validated (O'Connor, 1995, Koedoot et al., 2001), and the Cochrane Review reported that, when the DCS was used as a measure, 7 out of 10 decision aids were better than usual care at reducing decisional conflict, though only four significantly so (O'Connor et al., 2009). This is one way in which a PDA can be superior to health education materials: it can not only provide a detailed, specific and personalised focus on options and outcomes in order to prepare for a discussion with a clinician, but also assess its own usefulness in terms of how much its use has decreased the user's decisional conflict. This can be both a source of reassurance for the user of the decision aid, and a valuable source of research data.

Women also favoured a combination of formats, both electronic and paper-based though, as might be expected, younger women favoured web-based formats (definitive figures for the effect of age is not possible because e-forum participants did not give their age). Widespread computer use is now common in developed countries, including among those with mental health issues: even 11 years ago, Deegan and colleagues found that the vast majority of people using a mental health decision support centre would use computer-aided technology (Deegan and Drake, 2006). In 2019, this trend is likely to be considerably further advanced. Opportunities are now emerging to personalise decision aids still further by combining a web-based, interactive format with an app that can be used on a mobile phone. Such developments can only increase the potential accessibility of this new tool (and an internet-based aid could include downloadable sections which could be printed if

preferred). Such a format would also be able to accommodate regular review and updating of research content, all adaptations that were endorsed by most of the general psychiatrists interviewed. A cluster RCT of an electronic PDA (PANDAS) designed to improve decision quality in people with type 2 diabetes making treatment choices, which was designed to conform to the International Patient Decision Aid Standards (Appendix 12), provided good evidence for the utility and feasibility of use by clinicians with patients as well as improving decision quality by reducing decisional conflict, improving knowledge and promoting realistic expectations (Mathers et al., 2012).

General psychiatrists raised some interesting points regarding the most desirable format. Unlike perinatal specialists, who mainly see women who are euthymic and have proactively sought advice about pregnancy, many of them were treating very ill women who lacked capacity to make the decision to have a child or not. Although an important consideration, the DA would not be aimed at this population: if it is to be useful to someone considering pregnancy, it's essential that person has the mental capacity to comprehend its framework and content. Hence I would envisage the aid being offered by a clinician to someone who enquired about the issues around bipolar and pregnancy so that it could be used as a component of a structured decisional process, part of which would involve a consultation with a health professional.

## **6.5 Conclusion**

Results from this preliminary exploration of women's and professionals' views on the feasibility and usefulness of a decision aid for bipolar and pregnancy highlight both the need and appetite for such a tool, both among professionals and women themselves. The efficacy of decision aids for a myriad of medical conditions has been demonstrated by a recent update of the Cochrane Collaboration systematic review and meta-analysis of the use of aids in shared decision-making interventions, which examined 105 studies across a wide variety of contexts, involving 31,043 participants (Stacey et al., 2017). Reviewers concluded that there is high-quality evidence that, compared to usual care, people exposed to decision aids feel more knowledgeable, better informed and clearer

about their values, and they probably take a more active role in decision-making and have more accurate risk perceptions. They also reported that people were more likely to talk about the decision when using a PDA and cited further evidence that aids improve patient-practitioner communication. They found that decision aids decreased decisional conflict related to feeling uninformed (MD -9.28/100; 95% CI -12.20 to -6.36; 27 studies; N = 5707; high-quality evidence), indecision about personal values (MD -8.81/100; 95% CI -11.99 to -5.63; 23 studies; N = 5068; high-quality evidence), and the proportion of people who were passive in decision-making (RR 0.68; 95% CI 0.55 to 0.83; 16 studies; N = 3180; moderate-quality evidence).

In particular, the potential of PDAs for use in psychiatry looks extremely promising. As in Canada and the USA, the UK's National Health Service is being encouraged to develop them as a way to fulfil the ideal of patient-centred care while simultaneously improving outcomes and reducing costs (though the evidence base for these results is weak as yet). They are especially useful in areas of healthcare where decisions are complex, the evidence base is weak, and there is a high level of decisional conflict: all conditions which exist in the area of pregnancy decision-making for women with bipolar disorder. This thesis gives the first indication that a decision aid would be acceptable to women with BD considering pregnancy and to the professionals treating them. While acknowledging its limitations as a small-scale qualitative study with a selective sample, it demonstrates there is a need to provide women with better information and support to make pregnancy decisions and shows that a PDA is worth investigating as an option that might achieve that.

This thesis also offers an indication of how it would be viewed by clinicians, that is, they would broadly welcome such a development. Some raised concerns that such a tool might be too simplistic to fully capture the complexity of decisions influenced by so many competing factors; others that, conversely, if the PDA was extremely complex and detailed in its explication of all possible risks facing a woman with BD, it might increase anxiety. These are important points to bear in mind when attempting to design something that will be of genuine benefit. It might not, for example, be a good idea to ask a user to enter her personal medical history and family history of illness with a view to generating a 'risk' profile of the likelihood of illness in the perinatum.

Rather it might be better to encourage the user to gather such information in preparation for a discussion with her clinician.

Some professionals expressed concern about the potential harm such a tool could do, for example by providing too much information outside the consultation room and so increasing women's fear and anxiety, potentially leading to abrupt cessation of medication. To some extent this danger already exists with easy access to the worldwide web and this problem might be attenuated in a PDA by a thorough explanation of the limitations of the evidence base and a design which framed the PDA firmly in the context of an aid to the consultation with a clinician who would share in the decision-making process rather than as a stand-alone tool. The problem of being "overwhelmed" and made "overly anxious" by too much difficult to analyse evidence could be partially avoided by the use of advanced software design. The decision aid for antidepressant use in pregnancy, for example, employs a sophisticated 'click through' framework which allows the user to only access the level of detail she chooses to see (Vigod et al., 2019).

Furthermore, when it was made clear that the decision aid would explicitly state that it should not be used in isolation but was designed to be used in conjunction with seeking advice from a professional, professionals who had initially expressed doubts thought it was potentially helpful. It might help to empower women and their partners by giving them the opportunity to attend a consultation with their clinician fully appraised of the issues, more informed about the possible options open to them and having thought through their own feelings and opinions. This would not only enhance their confidence in raising issues and asking questions of the psychiatrist or GP but would also allow more time for discussion of a person's individual risk profile rather than education about research statistics. Preferably they would be able to consult an expert in perinatal mental health but if a woman only has access to advice from a clinician without such training, she would be in a better position to take part in making decisions regarding pregnancy and childbirth.

With the rapid advance of technological improvements and the concomitant increase in the use of computers, tablets and smart phones, it would seem most useful to

develop a web-based decision aid perhaps to be used in conjunction with a mobile phone application. Such a tool could contain information as described above together with interactive features to measure a woman's decisional conflict and with links to other sources of support, both professional and peer-led, building on the tool being developed for antidepressant use in pregnancy (Vigod et al., 2019). It could incorporate illustrations of various issues by including the views and experience of service users who had faced similar dilemmas (either in the form of written quotes or video clips). On the evidence of the current study, it would appear that such a tool would be welcomed by most women with BD and their partners, as well as by the majority of their clinicians. General psychiatrists, particularly those caring for women with severe illness, suggested that downloadable PDFs that could be printed out should also be incorporated to make the DA more accessible to this population who may not possess smartphones or laptops.

Another concern raised by this group was over the security of sensitive confidential information. For example, studies suggest that only a handful of mental health apps in commercial marketplaces conform to clinical guidelines (Torous and Roberts, 2017). For this reason among others, I believe any decision aid in this area would need to conform to the International Patient Decision Aid Standards (see Appendix 12), which require rigorous security standards (Elwyn et al., 2009). The evidence presented here also points to developing a 'protocol of use' which would involve a clinician as gatekeeper to the system (by providing patients with a personalised 'log in' for example). This would also allow an individual patient to engage in a preliminary discussion of how to use and interpret the PDA's content, hopefully reducing the danger of a user taking precipitate action before consultation with a health professional.

As a bipolar/pregnancy decision aid has the potential to improve the quality of decision-making in this challenging area which in turn could have a positive impact on outcomes, it seems desirable to develop a prototype which could be refined after piloting with both women and professionals, with a view to conducting a randomized controlled trial of its usefulness and impact. Recent research has described the disappointing level of implementation of decision aids in national health systems,

particularly in this country, (Elwyn et al., 2013, Legare et al. 2014). It would therefore be useful to also investigate targeting both patient and clinician - perhaps with some preliminary training for both - to improve the practice of SDM using decision-making tools, as suggested by the MAGIC (Making Good Decisions in Collaboration) programme (Joseph-Williams et al., 2017).

## **7 Overall Discussion, conclusions and implications**

### **7.1 Introduction**

This chapter will be describing what is new and distinctive about this research and how it has advanced understanding in this area. It will demonstrate how the different parts of the research relate to and build upon one another and describe the specificity and generalizability of the work while detailing its methodological and substantive limitations. It begins with a summary of the shortcomings of the evidence base, followed by an examination of this study's key findings and how they address gaps in the literature. The implications of these findings for research and mental health service practice are considered and the thesis' strengths and limitations scrutinized. I will then present a summary of my conclusions and reflections.

#### **7.1.1 Shortcomings of the evidence base**

Chapter 1's review of the literature relevant to pregnancy decision-making for women with bipolar disorder (BD) revealed the shortcomings of the evidence base and lack of decisional support for this group in the perinatal period. There is a need for reliable evidence on the safety of psychotropic drugs in pregnancy and breastfeeding, due in part to the difficulty of conducting clinical trials in this population (1.2.5.1). Studies on women in the perinatal period have often been conducted on small samples with significant methodological limitations due to major confounding and bias (Khalifeh et al., 2015a). The amount of research on bipolar disorder generally is disproportionately low compared to other mental health conditions (Kirtley, 2014). There are also particular shortcomings in the evidence base related to BD in the perinatal period as most studies on the adverse impacts of psychotropic medication on the fetus are either not stratified according to diagnosis or focus on women with depression (Cohen et al., 2006) and for some drugs like the anticonvulsants, the populations studied have been predominantly women with epilepsy rather than BD. In the burgeoning literature



on decision-making in mental health (examined in Chapter 6) a systematic review found only two out of 13 studies with BD-only samples and called for more BD-specific research to be done in this area (Fisher et al 2016). Only one US study has investigated the efficacy of preconception advice for women with BD (Viguera et al. 2002). Parenting with BD has been investigated in two small-scale studies (Venkataraman and Ackerson, 2008, Wilson and Crowe, 2009) and, since this thesis was undertaken, two further small qualitative studies have been published, one on pregnancy medication decision-making (Stevenson et al. 2016) and a Dutch study about views on family planning (Stevens et al. 2017).

### **7.1.2 This thesis' contribution to the evidence base**

The dearth of qualitative research on BD in the perinatal period revealed by Chapter One's literature review led me to investigate the factors that influence women with BD's decision-making in the perinatal period. The lack of research focused on BD also determined the design of my systematic review and metasynthesis of the qualitative literature on preconception to motherhood as, because there was so little research on BD and pregnancy, it was necessary to widen the review beyond a single diagnosis to include *all* women with severe mental illness (SMI). The resultant meta-synthesis (Chapter 2) synthesized the growing literature on the views of women with SMI and was the first systematic review to give an overview of the qualitative literature in the area of women's mental illness in relation to having children from preconception to parenting. Despite the heterogeneity of the studies included, this review underscores the challenges facing women with SMI when they have children and the ways in which issues such as stigma and fear of custody loss mitigate against the establishment of a meaningful therapeutic relationship with health professionals. In particular it highlighted the central importance women with SMI assign to motherhood, and the level of anxiety health professionals from different disciplines experience when caring for women with SMI at this time.

Having identified a lack of qualitative research focused on BD, I designed a study to investigate the factors influencing the decision-making around pregnancy of women

with this diagnosis, the psychiatric diagnosis that carries the greatest risk of relapse at this critical time. In-depth interviews with 21 women who were considering pregnancy, currently pregnant or had recently given birth were supplemented by the testimonies of 50 women via the internet forum of the charity Bipolar UK. Data analysis identified five superordinate themes: *Centrality of motherhood; Fear; Stigma; Contextual factors and Experience of services* (Table 3-2). The *Centrality of motherhood* played a major role in women's narratives in this study, echoing its significance to the wider group of women with severe mental illness described in Chapter 2's systematic review and metasynthesis. For the first time, this study highlighted the different treatment women felt they received because they had a diagnosis of bipolar disorder rather than depression (3.3.2.3.3). This thesis is also the first to highlight the stigma experienced by women in relation to breastfeeding or their 'failure' to do so because they were taking medication (3.3.2.3.4). A systematic review of mothers' experiences of bottle-feeding (whether from choice or due to problems experienced) reported similar feelings of shame and inadequacy (Lakshman et al. 2009) but the concerns of women with BD – or indeed any mental illness – have not been reported previously; it is noteworthy because being subjected to such stigma might be associated with a deterioration in a woman's mental state postnatally.

Other new findings included the first recording of ways in which women with BD were proactively considering methods of having children without the risks that pregnancy poses for them, including surrogacy, fostering or adoption (3.4.1.3). The experience of discrimination in attempts to access fertility treatment was also described for the first time (by an e-forum participant (3.3.2.3.3)). The health professionals with whom they raised these issues were unable to give them information and many women did not know where else to turn. On the question of a woman with a mental illness being able to adopt a child, for example, NHS Choices is vague, stating only that: "Mental health issues are given careful consideration and, like physical health issues, do not necessarily make someone unsuitable to adopt." (NHS, 2015). But most women interested in exploring this path as a means of avoiding a psychotic episode worried that their mental illness would exclude them from such opportunities (though they didn't expect the relevant agencies to admit that this was the reason). Several women

also raised the issue of whether delivery by Caesarian section would reduce the risk of postnatal mental illness, a topic which has not been discussed in the literature before (3.3.2.5.5). This was of particular interest to women with BD because it could give them some control over the timing of the birth and avoid the sleep deprivation associated with protracted labour, sleep being so essential to people with BD, especially females (Saunders et al. 2015).

This is the first study to include the perspective of health professionals on pregnancy decision-making for women with BD, with data from both general adult psychiatrists and perinatal mental health specialists examined in Chapter 4. Collecting the views of these professionals was an important way to build upon the insights gained from the women's study as they are an integral part of the decision-making process and women had raised many issues regarding their attitudes and conduct. I therefore invited a group of perinatal specialists from different professions to a focus group and interviewed 14 general psychiatrists about their views on advising women with BD about pregnancy and, having reported the results (Chapter 4), I proceeded to compare their views with those of the women in Chapter 5. This comparative analysis highlighted the fact that professionals didn't appear to appreciate the central importance of motherhood to women they were treating. This appeared to be largely due to the professionals' preoccupation with risk. Bipolar disorder can result in very severe, potentially life-threatening episodes of illness, particularly when triggered in the perinatal period as the Confidential Enquiries into Maternal Deaths have too often described (Knight et al., 2015). It is perhaps understandable, therefore, that psychiatrists view pregnancy from this perspective; particularly those working in settings where they chiefly see women with severe illness, multiple previous admissions and numerous comorbidities.

Many women expressed their fear at becoming extremely ill, but for most this was outweighed by their motivation to have a child. In order to achieve this goal, they wanted information on how to stay well during the perinatal period but this was hampered by stigma, inadequate services and insufficient professional training, as well as by the shortcomings of research in this area. Their unmet need for information

which this study identified as a major sub-theme was corroborated by a later systematic review and meta-synthesis of qualitative research on the experience of mental health problems in the antenatal or postnatal period for women in the UK (Megnin-Viggars et al., 2015).

Data from the interviews and internet forum contributions described in Chapter 3 highlight the anxiety felt by women when contemplating pregnancy and the postpartum, most acutely around the issue of exposing their child to the adverse effects of psychotropic medication or becoming very ill if they choose instead to stop taking what has been prescribed for them. This is in line with previous research indicating a high level of maternal anxiety over the teratogenicity of medications for depression in pregnancy (Price and Bentley, 2013) though no research had focused on bipolar disorder before. Many women also have to make a number of important treatment decisions when already pregnant, and these include not just medication but options around the birth, breastfeeding and postnatal care. The conclusions of a pilot qualitative study on decisions on psychotropic medication during pregnancy faced by women with SMI, which included 8 women with BD (Stevenson et al., 2016), chimed with results from this study in that they found decision-making in this area very complex and reported that women were disappointed and made more anxious because professionals were not able to give them better evidence-based information to help them make decisions.

A later Dutch study which interviewed 15 women with BD about their thoughts on family planning and pregnancy (Stevens et al., 2017) corroborated themes found in the current study by identifying medication worries, heritability of BD, doubts over mothering capabilities and the need for support from partner, family and health professionals as important themes. The current study is distinctive in that I purposively recruited pregnant women and women who had had children as well as those considering parenthood, whereas the Dutch sample were all childless. This broader sampling frame generated additional themes which arose from experience of childbirth such as the consideration of ways to avoid the sleep deprivation associated with a long labour and issues related to breastfeeding and postnatal care.

The superordinate theme *Stigma* was also prominent in the data from both women and professionals, with a consensus among all groups that it was a problem which could have a detrimental effect on shared decision-making. In addition to commenting on their interactions with psychiatrists, women also expressed views on the attitudes of several other professionals with whom they came into contact at this time: maternity staff (from midwives to obstetricians); general practitioners; health visitors; social workers and psychiatric nurses. The fact that women with BD found it so hard to access information on how best to approach pregnancy (and when they asked for specialist advice they were often denied it), was seen by many participants as discrimination. Women and their families felt they had to become proactive and do research themselves as so little information was available to them. It was striking that the data from women, specialists and general psychiatrists revealed a broad consensus on what was required from services though patchy provision and inequity of access meant that this was not always delivered. There is also confirmation in the data of all three groups that more training is needed for all professionals in this area to increase knowledge and reduce stigma, themes later endorsed by an integrative review of midwives' attitudes to perinatal mental health which concluded that better co-ordination and integration of services was necessary to deliver optimum care (Noonan et al. 2017).

The comparative analysis also revealed the importance of the theme *Timing* and some of the reasons behind the discrepancies between women and specialists on the one hand and the general psychiatrists on the other regarding when to first discuss the challenges of pregnancy for women with BD. The two former groups agreed that it would be beneficial if women were given some information about the complexities of perinatal decision-making when, or soon after, they were diagnosed, as is recommended by NICE (2014). Both groups attested to the fact that this did not routinely happen despite it having the potential to avoid problems later when women came to consider having children. As it is normally general adult psychiatrists who are the professionals responsible for making such a diagnosis, it was useful to hear their views on this matter. This discussion revealed a variety of reasons why this matter was not routinely discussed with *all* women with BD of childbearing age including time

pressure and concerns that it might “scare” women and deter them from taking their medication. This also highlighted that the general psychiatrists were often treating a distinctly different group of women to the specialists: more severely ill, socially isolated and with significant comorbidities. Unlike the women seen by specialists, their patients were rarely seeking preconception advice but were often struggling to stay well. Particularly for those psychiatrists operating in high dependency units and in urban settings, capacity was a prominent issue and interviewees expressed concern that “opening up the pregnancy conversation” at the wrong time might cause some women to stop taking their medication and so put their health at risk. They were heavily focused on keeping their patients well and paid more attention to how well-informed or otherwise they were on the subject of *avoiding* pregnancy. It was noteworthy that all the female psychiatrists interviewed (6 of 14) emphasised the importance of making all women with BD of childbearing age aware of the issues around pregnancy, whereas it was less fundamental for their male colleagues.

Another difference highlighted by the comparative analysis in Chapter 5 was the specialists’ wider knowledge of other resources to which they could signpost women, such as information and support provided in the Third Sector which might be useful to them. The idea of producing a patient decision aid (PDA) specifically for women with BD making decisions around pregnancy was investigated in Chapter 6 and welcomed by all groups as having potential. This study was the first to elicit the views of women with BD on this idea and also the first to ask health professionals working with this population their opinions on the usefulness or otherwise of such an aid. The response was generally positive, with reservations expressed by some that use of such a tool needed to be ‘gatekeepered’ by a professional able to offer support if needed. Results from this thesis correspond to an online survey of the views of people with affective disorders conducted in Germany which included responses from 210 people with BD (plus 112 with unipolar depression) (Liebherz et al., 2015). They concluded that information was extremely important to this population and are using this data to develop decision aids for an e-mental health portal.

## **7.2 Strengths and limitations**

Some of the strengths and limitations of individual studies have been discussed previously (Chapters 2, 3, 4 and 5). Here I intend to highlight those that apply more generally to the whole thesis.

### **7.2.1 Strengths**

#### **7.2.1.1 Focus on bipolar disorder**

The fact that this study focuses on the needs of women with a particular diagnosis, bipolar disorder, is one of its strengths. In an era moving ever closer towards personalized medicine (Schork, 2015), Burke and Psaty, 2007, Simon and Perlis, 2010), it is important to differentiate between clinical groups when conducting research to improve its usefulness in real world settings. The unique needs of women with BD when considering pregnancy have been largely ignored internationally (Viguera et al., 2002) and the only systematic review on Pregnancy and Bipolar Disorder described the “paucity” of research in this area and called for it to be urgently addressed (Sharma and Pope, 2012). Research into BD generally is disproportionately low compared to other mental health disorders (Kirtley, 2014) and there have been few qualitative studies (Todd et al., 2013, Sajatovic et al., 2005). The two studies in the area of pregnancy decision-making published after results from this study appeared (Dolman et al., 2016) had smaller samples - 12 women in the Netherlands (Stevens et al., 2017) and 8 in the only UK study (Stevenson et al. 2016) - and did not include the views of professionals. Testimony from women in this thesis also supports the importance of sleep disruption and deprivation as likely triggers for women with BD highlighted in a recent study (Lewis et al., 2018).

#### **7.2.1.2 Use of qualitative methods**

The use of qualitative methodology was highly appropriate for this study as when I undertook the project the views of women with BD on pregnancy decision-making

were not represented in the literature and it is valuable to hear what protagonists themselves consider to be the most important issues in order to inform more prescriptive research and improvements in service provision (Mays and Pope, 1995). Triangulation of the data was employed in a number of different ways to serve a dual purpose: confirmation and completeness (Breitmayer et al., 1993). Triangulation was used *within* the study with women with BD (by using data from an e-forum as well as interviews) to confirm information but also to some extent to *complete* the picture (for example by accessing the views of women who had chosen to remain childless because of their BD). This data was then further triangulated by gathering the views of two sets of health professionals to gain a more comprehensive understanding of the decision-making process and to hear a different perspective on some of the questions raised by women, for example why the challenges of pregnancy hadn't been discussed with them sooner (Patton 1999, Carter et al., 2014). In this way each different part of the project built upon the results from the former: women had a lot to say about the way general and specialist perinatal psychiatrists differed in their approach so it was useful to elicit the views of both groups.

#### **7.2.1.3 Generalisability**

Data was generated from the testimonies of 71 women with BD, representative in terms of ethnic profile, age and different stages of the perinatal period, from preconception to postpartum (Table 3-1). The collection of data via an internet forum was novel and a valuable part of the thesis in addition to its usefulness as a means of triangulating the data (as described above), because the particular methodology used was unusual and may prove useful in future studies that use the internet as a means of collecting data. The focus group of perinatal specialists represented a good spread of different professionals and there was some variety in both the geographical location and type of service worked in by the general psychiatrists. This study was also the first to be focussed on women with BD in the perinatal period to be conducted in the UK. Our National Health Service and care pathways involving GPs and secondary care are internationally unique so it was useful to provide information on British women's experiences of services, considering the only two qualitative papers in the systematic



review were conducted in the US and New Zealand (Venkataraman et al. 2008 and Wilson and Crowe 2009 respectively). Since then a British study recording women with SMI's views on medication in pregnancy including 8 women with BD (Stevenson et al. 2016) and a Dutch study (Stevens 2017) have been published (described above).

#### **7.2.1.4 Researcher's status as a service user**

As mentioned earlier in this work, I have conducted this study as a service user researcher, a type of investigator whose unique perspective is increasingly valued and encouraged in health service research settings, notably in the UK (Veseth et al., 2017, Rose, 2015) Beresford, 2005, Thornicroft and Tansella, 2005). I was in part prompted to undertake this work as a doctoral project because of my personal experience as a woman with BD who has had two pregnancies (one followed by hospitalization for postpartum psychosis). I view the experience I brought to this investigation as largely of benefit for several reasons. I have an understanding of the issues which was useful when formulating the topic guides (especially considering the absence of research on this subject). My experience was very helpful when recruiting members of this quite difficult to reach population as some women felt they would be more comfortable talking to me about highly stigmatized subjects (and some were keen for the opportunity to talk to someone else who had had a similar experience to them). I also believe interviews yielded richer data because women felt more able to be frank with me and I appreciated when and how to pursue certain sensitive issues.

#### **7.2.2 Limitations**

However, my personal experience could also be seen as potentially problematic as there was a risk of losing perspective and perhaps bringing one's own prejudices and biases to the study. As described elsewhere, I attempted to guard against this danger by having independent researchers analyse portions of the data and all transcripts and analysis were also read by my first supervisor. I have also acknowledged the possibility that general psychiatrists interviewed by me might have felt constrained in some way by my association with a patient group they treat. My role as a researcher was further

complicated by my activism as a campaigner to improve perinatal mental health services available to women with SMI; I have tried to be ever vigilant to avoid this influencing my research enterprise.

In addition to the small numbers of professionals participating (11 specialists and 14 general psychiatrists) it is also a limitation of the study that it lacked representation from GPs who are often consulted for preconception advice. Increasingly, partners accompany women with BD to appointments to discuss these issues, so it would have been preferable to include first rather than second-hand accounts of their experience. It must be noted too that the sample of women interviewed in Chapter 3's study was selective as half of the women were recruited via the preconception clinics of specialist perinatal psychiatrists, a group which may be different to the general population of women with BD. The methods used here were not able to garner information on what *actually* happens in consultations and the use of different methodology such as the recording of conversations between health professionals and women with BD may have given informative data on what actually occurs in such meetings. This method could have provided valuable insight into the dynamics of the consultation and would not have been subject to recall bias.

As discussed above, this study was the first to focus on women with BD's experiences in the UK but this does not mean its results are generalizable to other countries. Internationally, perinatal services are extremely heterogeneous (for example, Mother and Baby Units as they exist in the UK are very different to most other parts of the world such as in the USA, where babies cannot stay with their mothers in the unit overnight). The calls for improved access to high quality perinatal mental health services by women and professionals in this study are being echoed in other countries, the vast majority of which are even less well-served than the UK. It is important to consider the cost implications of providing the comprehensive services women are calling for, even more so in non-Western settings (Rahman et al., 2013).

### **7.3 Implications for further research**

The findings in this thesis highlight the dearth of research related to the pregnancy decision-making of women with BD despite them being the group with the highest risk of relapse at this time. Both women themselves and health professionals expressed frustration at the lack of reliable research to guide the complex decisions that need to be made. If a higher proportion of these women are to stay well in the perinatal period, the treatment decisions they make need to be informed with better quality research evidence – an advance that was called for by women and professionals in this study. This recommendation has been endorsed by NICE (2014) which has specifically called for more research on “the safety of drugs for bipolar disorder in pregnancy and the postnatal period”. Qualitative evidence describing the views of women and their clinicians in this area, such as that presented in this thesis, can provide useful context to help shape the design of future studies and perhaps a next step would be to record consultations and analyse them. It would also be helpful to conduct research with GPs and more community psychiatrists to elicit their views of this area of healthcare.

If women were provided with more robust evidence on the teratogenicity and any longer-term neurodevelopmental impact of the medications they take and the efficacy of alternative treatments, it can be conjectured that fewer of them would stop taking their treatment when they become pregnant. The large majority of women taking psychotropic medication stop taking it in pregnancy, with UK researchers finding that only 38% (107 of 279) on atypical antipsychotics and 19% (39 of 207) of women on typical antipsychotics before pregnancy are still taking them by the third trimester (Petersen et al., 2014b). This medication cessation has a direct effect on relapse rates (Viguera et al., 2007) with all the concomitant morbidity, hospital admissions, family anxiety and potential disruption of the mother/child relationship that that entails. As evidenced in this study, women often stopped taking their medication because of poor advice from professionals resulting from a lack of knowledge or training so it would be beneficial to know whether improving the quality of preconception counselling would affect rates of medication cessation and its associated greater morbidity. The only investigation into the effect of specialist preconception counselling was done in the US

in 2002 by Viguera and colleagues and they were focused on whether specialist counselling changed women's decision about whether to have a child at all as 45% of the sample had been advised by their usual practitioner to avoid pregnancy (63% of those decided to start a family after consulting a specialist perinatal psychiatrist) (Viguera et al., 2002). Considering the fears expressed by women in this study about the possible teratogenic effects of taking psychotropic medication in pregnancy, it would also be helpful to conduct more research on alternative treatments. NICE (2014) recommends considering psychological interventions for women with BD particularly when medication is changed or stopped. Some women in this study called for access to such therapies, though others expressed doubts about their usefulness, especially in the immediate postnatal period, so more evidence on their efficacy for this population is needed.

It would also be useful to know whether access to high quality counselling has any effects on pregnancy or birth outcomes – or indeed on the longer-term wellbeing of mother and child. According to women in this study, receiving preconception advice and support lowered their anxiety levels considerably and the reported reduction in stress may in itself make a contribution to ensuring a healthier pregnancy and delivery. Viguera called for more studies in broader samples of women of childbearing age with BD to clarify the unique reproductive health needs of what she called “this special and understudied population”. To date this subject has received only preliminary attention, with one service evaluation report published (Wieck et al., 2010). Research needs to be undertaken to discover whether access to preconception counselling improves outcomes. If this proved to be the case, it would be useful evidence to support comprehensive improvements in perinatal mental health services, particularly in countries with only a skeleton service. It was also suggested by women in this study that peer support would be helpful (3.3.2.5.5.4). Interventions involving peer support have proved effective for women at high risk of developing postnatal depression (Dennis et al. 2009, (Kamalifard et al., 2013) but research is needed into the effectiveness of peer support in pregnancy and postnatally which is aimed specifically at women with BD, as was requested by women in this study.

Lastly, this thesis suggests the development and testing of a decision aid for women with BD making decisions around pregnancy would be welcomed by patients and health professionals. Research on producing a patient decision aid (PDA) to help pregnant and breastfeeding women with mental disorders make informed decisions about their care was recommended by NICE in 2007 when it stated that, as part of the process of discussing the risks of treatments during pregnancy and the postnatal period, health professionals should “if possible use decision aids in a variety of verbal and visual formats that focus on an individualized view of the risks” (NICE, 2007). So far only a PDA designed for women taking antidepressants in pregnancy has been developed and piloted (Vigod et al., 2019). As discussed in Chapter 6, the decisions facing women with BD are far more complex and potentially have more serious consequences than those facing women with mild to moderate depression. To produce such a tool would be challenging but, from the evidence presented here, if such an aid were to be developed and evaluated by means of a randomized controlled trial, it could have the potential to make a contribution to improved decision-making for this group and perhaps, as a consequence, also contribute to reducing relapse rates. However, with research lacking, it is not possible to say whether a PDA is the best way of assisting decision-making in this area; perhaps providing better access to up-to-date information and signposting to other resources (for example, by creating a website on the subject) would be just as helpful.

## **7.4 Implications for services**

One of several implications for services arising from the conclusions of this study is the need for psychiatric services to inform women diagnosed with BD about the risks of pregnancy, as recommended by NICE (2014). Some general psychiatrists were very aware of this but others interviewed in this study were not and a consistent approach across services would give women more time to prepare and would perhaps contribute to better decision-making. Services can also learn from the problems of poor collaboration between different professional groups such as psychiatrists and obstetricians, midwives and health visitors, which were identified in this study and

have been highlighted elsewhere (Megnin-Viggars et al. 2015, Noonan et al. 2017). NICE has recommended that there should be clearly specified pathways to ensure access to assessment and treatment, and clinical networks should be established to facilitate these improvements (2014). In particular women called for better access to Mother and Baby Units in England, provision of which was identified as inequitable in 2009 by Elkin and colleagues, who highlighted the need for quantitative and qualitative research to identify their most effective components and the population who benefitted most from using them.

Evidence from this thesis has contributed to that evidence base and has informed a national campaign to improve perinatal mental health services, which encouraged a government commitment to fund more units and end the current postcode lottery (MMHA 2018). The cost implications for a national health service increasingly under pressure are not insignificant but it has been hypothesized that improving services in this previously overlooked area will save money in the long run as well as improve outcomes for mothers and children (Bauer et al., 2014). Bauer and her colleagues estimated that a case of postpartum psychosis cost society approximately £53,000. Though high, this is almost certainly a substantial underestimate due to a lack of evidence about both the short and long-term impacts on the child of a mother suffering a psychosis. The estimated public sector costs relating to the mother are about £25,000 per case, more than double the equivalent costs for depression and anxiety (just under £10,000 each). Research is also required to determine the best configuration of perinatal mental health services and this has now been commissioned to commence in June 2019.

Another potentially costly suggestion made by all three groups in this study was that health professionals encountered during the perinatal period needed more training in perinatal mental health. This problem needs addressing and the Royal College of Psychiatrists is now running government-funded, specialised perinatal mental health training courses for its members. The findings of this thesis are informing that training directly as its results form part of training sessions delivered to psychiatrists by me and a fellow expert by experience entitled 'What women want from their psychiatrists'. It was also pointed out by women with BD that other staff they encountered in health

settings would benefit from some training on what bipolar disorder is and its implications in the perinatal period, particularly the symptoms and severity of postpartum psychosis so that they would be able to recognise it more quickly and offer help. This accords with a report from the Royal College of Psychiatrists in this area which states that “Good perinatal mental health services should include an education and training programme, which should be provided for non-specialists involved in the care of pregnant and postpartum women including general psychiatric teams, GPs, midwives, health visitors and psychological treatment services such as IAPT” (R.C. Psychiatrists, 2015). Results from this study have therefore been presented in a number of training sessions for maternity staff, obstetricians, GPs and other professionals involved in the care of women in the perinatal period, and at a number of national and international conferences (see Appendix 13). Better training in perinatal mental health (especially where delivered by experts by experience) should help to diminish the prevalence of stigmatizing attitudes among health professionals towards women with mental illness who become mothers – or who *want to* become mothers (Jeffery et al. 2013).

Such training will need to emphasize the damaging effects of new mothers being stigmatized for bottle-feeding their infants and the importance of the ‘centrality of motherhood’ – the strength of many women’s determination to have a child regardless of the effect it might have on their health – as results from this study show that professionals did not appreciate the importance of this factor. Public Health England are currently examining how to provide perinatal care in secondary mental healthcare services such as Early Intervention and Community Mental Health Teams and are in a good position to ensure information given to women is consistent and up to date. In recent years, there has been an increasing focus on preconception care, with a recent Lancet Series of reports calling for “heightened awareness of preconception health, particularly regarding diet and nutrition” (Hindley et al., 2019). The fact that, despite political declarations that there should be parity of esteem between physical and mental health, reference to maternal mental health was omitted is disappointing (Wilson et al., 2018). For women with BD, the provision of timely, high quality preconception advice and support can not only contribute to the prevention of

illness in the perinatal period, but it could also reduce anxiety in pregnancy, a condition which can have an adverse effect on the fetus (Talge et al., 2007, Glover et al., 2016).

## **7.5 Summary and reflections**

I was motivated to undertake this research project by my awareness of the difficulties women with BD face when trying to get information and advice on the decisions they have to make if they want to have a child. I have gained an insight into the multiplicity of factors which affect their decision-making, and a greater appreciation of the fact that these not only pose a challenge for women with BD but also for the health professionals whom they consult. More research in this area is needed, as NICE guidelines have repeatedly stated (2007, 2014). The difficulties faced by women with BD making decisions around pregnancy are exacerbated by stigma against women with mental illness as mothers. This area deserves more attention, both to prevent and/or alleviate the suffering of many women and their families, but also to investigate ways of understanding and preventing the adverse outcomes that might be suffered by their children. In addition, as the evidence of transgenerational transmission of vulnerability to mental illness continues to mount (Lewis et al., 2015, Blewitt and Whitelaw, 2013) such research also has the potential to reduce the overall burden of psychopathology in our society.

Testimony from the 70 women with BD in this study confronted with difficult decisions around pregnancy illustrates the risks and high stakes involved and yet their fear at confronting these was so often outweighed by the strength of their longing to have a child. It was surprising that neither group of professionals appeared to appreciate the power of this maternal urge which drove many women to take significant risks with their health. To a greater or lesser extent, the professionals' primary focus was on the risks that pregnancy represented. The broader scope of this study, encompassing what women and clinicians suggest could be done in practical terms to improve existing services, has provided valuable evidence when highlighting these problems more widely and considering possible remedies. All groups recognized the need for more



understanding of bipolar disorder among the wider NHS workforce, but improving knowledge in this area has its own challenges, especially as BD is a relatively uncommon condition which they will only encounter infrequently. As a service user researcher, I am trying to contribute to the resolution of this problem by using results from this study in training programmes for general psychiatrists and for a wider group of health professionals (Appendix 13).

Lastly, the findings reported in this thesis give the first indication that a decision aid could be useful in this context and would be acceptable to women with BD considering pregnancy as well as the professionals treating them. This is not to say that this is the only way of addressing the information needs of this population and assisting them with the difficult decisions they face. Detailed websites and downloadable leaflets capable of regular update might be similarly helpful and perhaps more appropriate and cost-effective in some settings, particularly in lower income countries. Results from this thesis indicate that research to test these possibilities would be welcomed by service users and professionals alike.

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## Appendices

### Appendix 1: Data Extraction Form for studies on the views of women with SMI

#### Study Characteristics

Please enter the dates of data collection:

Year of start of data collection	
Year of end of data collection	

Please select the study design:

Study Type	If yes tick box(es)	Please specify if required
In depth interviews		
Semi structured interviews		
Focus groups		
Ethnography		
Other (please specify):		

Please select the sampling method used in the study:

Sampling Method	If yes, tick box(es)	Specify if required
Random sampling		
Purposive sampling		
Theoretical sampling		
Convenience sampling		
Snowball sampling		
Other (please specify)		



Not specified		
---------------	--	--

Please select the primary method of data analysis:

Analysis Method	If yes, tick box(es)	Specify if required
Grounded theory		
Framework analysis		
Content analysis		
Narrative analysis		
Conversation analysis		
Discourse analysis		
Other (please state)		
Not specified		

Please select the healthcare setting to which the study relates:

Setting	If yes tick box(es)	Please specify if required
Community-based mental healthcare		
Outpatient mental healthcare		
Inpatient mental healthcare		
Other mental healthcare setting (please specify):		
Not specified		

### Study Population

Please enter the study's inclusion criteria:

Please enter the study's exclusion criteria:

Please enter the country(s) in which the study was conducted:

--

Please enter the number of males and females in the study sample:

Sex	n
Males	
Females	

Please enter details of the age of the study sample:

	Age (yrs)
Youngest	
Oldest	
Mean	
Standard deviation	
Not specified	

### **Mental Disorder**

Please select the categories of mental disorder recorded for the sample (tick as many as apply and provide further detail if available):

Category of Mental Disorder	N
Schizophrenia	
Schizoaffective disorder	
Bipolar disorder	
Depression (if perinatal, please specify)	
Other (please specify)	
Not specified	

### **Outcomes**

Please enter any notes about the identified primary constructs

Please enter any notes about the identified secondary constructs

## Appendix 2: Data Extraction Form for studies on views of health professionals

### Study Characteristics

Please enter the dates of data collection:

Year of start of data collection	
Year of end of data collection	

Please select the study design: questionnaires

Please enter information about response rate:

Please select the healthcare setting to which the study relates:

Setting	If yes tick box(es)	Please specify if required
Community-based mental healthcare		
Outpatient mental healthcare		
Inpatient mental healthcare		
Other mental healthcare setting (please specify):		
Not specified		

Please select which types of healthcare workers to which the study relates:

Healthcare Worker	If yes tick box(es)	Please specify if required
Psychiatrist		
Other doctor (please specify)		
Psychologist		
Psychiatric nurse		
Other nurse (please specify)		
Nursing assistant		

Care coordinator		
Social worker		
Other (please specify)		
Not specified		

### Study Population

Please enter the study's inclusion criteria:

NS
----

Please enter the study's exclusion criteria:

NS
----

Please enter the country(s) in which the study was conducted:

--

Please enter the number of males and females in the study sample:

Sex	n
Males	
Females	
Not specified	

Please enter details of the age of the study sample:

	Age (yrs)
Youngest	
Oldest	
Mean	
Standard deviation	
Not specified	

**Mental Disorder of patient group**

Please select the categories of mental disorder recorded for the sample (tick as many as apply and provide further detail if available):

Category of Mental Disorder	If yes tick box(es)	
Schizophrenia		
Schizoaffective disorder		
Bipolar disorder		
Depression (if perinatal, please specify)		
Other (please specify)		
Not specified		

**Outcomes**

--

## Appendix 3: Interview Topic Guide for pregnant women

I want to ask you about your experience thinking about having a baby and how it might have been affected by your bipolar disorder. I'm particularly interested in this subject because I have bipolar myself and I have had 2 children, and I know that many women in our situation think a lot about what might happen when we have children. If it's okay with you, I'd like to hear what your thoughts are on the matter and then afterwards if you want I can give you some information leaflets that you might find useful and we can chat about it more generally.

Can I ask you a bit about your illness first – when you were first diagnosed and how it affects you? How have your family been about it? What about your partner?

How is your pregnancy? Are you feeling well?

Can I ask you about when you first considered having children? What factors were important to you when you were thinking about it?

*What is the significance of your bipolar disorder in your decision-making?*

What, for you, were the most important considerations?

Have you discussed this matter with your partner, family and/or friends?

*If no, is there a reason for that? If yes, how did they react?*

*[What is the attitude to mental illness in your community?]*

*[What is the attitude to having children?]*

How much do you know about having a baby as a woman with bipolar?

Do you feel you know what you need to know?

*If no, what do you think would be helpful?*

Have you ever discussed this matter with any medical professionals?

*If so, how did that go?*

When you discussed it with the doctor, how did you feel about the conversation? *Did you make the decision in the way you wanted – with their help for instance?*

*[If it hadn't been possible to see a perinatal specialist, what difference would that have made?]*

How you would like it to be? *How much help would you want from your doctor, for instance? Do you see it as a big responsibility or do you prefer to make the decisions yourself?*

*What about over medication?*

What sort of information do you think you need to know, and how do you think that would be best delivered (in what format?)

Is there anything you think is relevant about these issues which we haven't discussed?

## Appendix 4: Interview Topic Guide for women who had given birth

I want to ask you about your experience thinking about having a baby and how it might have been affected by your bipolar disorder. I'm particularly interested in this subject because I have bipolar myself and I have had 2 children, and I know that many women in our situation think a lot about what might happen when we have children. If it's okay with you, I'd like to hear what your thoughts are on the matter and then afterwards if you want I can give you some information leaflets that you might find useful and we can chat about it more generally.

Can I ask you a bit about your illness first – when you were first diagnosed and how it affects you? How have your family been about it? What about your partner?

*When you had your baby, was the pregnancy planned? What things did you think about when thinking about having a baby?*

*What was it like being pregnant? Did you feel well? Any physical health problems or were you depressed or anxious at all?*

What, for you, were the most important considerations?

Do you think the fact that you have bipolar makes any difference to your child?

Have you discussed this matter with your partner, family and/or friends?

*If no, is there a reason for that? If yes, how did they react?*

*[What is the attitude to mental illness in your community?]*

*[What is the attitude to having children?]*

Have you ever discussed this matter with any doctors or nurses - or other medical professionals?

*If so, how did that go?*

How much do you know about having a baby as a woman with bipolar? Do you feel you know what you need to know?

*If no, what do you think would be helpful?*

When you discussed it with the doctor, how did you feel about the conversation?

*Did you make the decision in the way you wanted – with their help for instance? If you had seen a perinatal specialist, would that have made a difference?*

How you would like it to be?

*[for instance, if you think about having another child?], how much help would you want from your doctor, for instance? Do you see it as a big responsibility or do you prefer to make the decisions yourself? What about over medication?*

What sort of information do you think you need to know, and how do you think that would be best delivered (in what format?)

Is there anything you think is relevant about these issues which we haven't discussed?



## Appendix 5: Social/demographic questionnaire

**ID number:**

**Person:**

**Date:**

Date of Birth: .....

Relationship status:

**Co-habiting**

**Married**

**Single**

**Divorced**

**Other** (please specify) .....

Ethnicity:

**White**

**Black-African**

**Black Caribbean**

**Black Other**

**Indian**

**Pakistani**

**Bangladeshi**

**Chinese**

**Other** (please specify): .....

**Your Employment and Education Details:**

Are you currently employed?

**Yes**

**No**

What is your current job status?

**Full-time**

**Part-time Unemployed**

**Student**

**Full-time mother**

**Other** (please specify): .....

**Job Title:** .....

What is your highest level of education?

**NVQ 1/2**

**NVQ3**

**GCSE**

**A-LEVEL**

**DEGREE OR ABOVE**

**OTHER QUALIFICATIONS**

Please specify: .....

**YOUR PARTNER'S: Employment and Education Details:**

Is your partner currently employed?

**Yes**

**No**

What is your partner's current job status?

**Full-time**

**Part-time**

**Student**

**Unemployed**

**Other** (please specify)

What is your partner's highest level of education?

**NVQ 1/2**

**NVQ3**

**GCSE**

**A-LEVEL**

**DEGREE OR ABOVE**

**OTHER QUALIFICATIONS**

Please specify.....

### **Household Information**

Who normally lives at your address? Please tick which apply:

	Tick Here	How many?
Daughter		
Son		
Partner		
Mother/father		
Grandparent		
Uncle/Aunt/Cousin		
Friend		
Siblings		

Other, please specify .....

### **Pregnancy information:**

How many children do you have? .....

Any other pregnancies: Miscarriages ..... Abortions .....

Children taken into care.....

**If you are pregnant,**

Number of weeks of gestation: .....

Estimated Date of Delivery (EDD): .....

**Where do you expect to have your baby if all goes to plan?**

Local hospital ..... Mother and Baby Unit ..... At home .....

**Have you discussed your bipolar disorder in relation to your pregnancy with any health professionals?**

.....

### **MENTAL HEALTH**

#### **CURRENT MENTAL HEALTH**

**What is your mental health diagnosis? Please state if it is described as a dual diagnosis with another condition.**

.....

**Are you currently receiving treatment, including medication, from a GP, psychiatrist, counsellor/therapist etc. for a mental health condition?**

**YES** (if yes please specify below)

**NO**

.....

**PREVIOUS MENTAL HEALTH**

How old were you when you received a diagnosis of bipolar disorder? .....

Had you been suffering symptoms for a time prior to this, if so how long before, approximately?

.....

Did you receive treatment from GP, psychiatrist, counsellor/therapist, etc...?

**YES** (if yes please specify below)

**NO**

.....

## Appendix 6: Participant Information and Consent form

**Institute of  
Psychiatry**

**at The Maudsley**

**Health Service  
& Population  
Research  
Department**

Section of Women's  
Mental Health

PO 31  
De Crespigny Park  
Denmark Hill  
London SE5 8AF  
Tel +44 (0)20 7848 0851  
Fax +44 (0)20 7277 1462  
www.iop.kcl.ac.uk

**KING'S**  
*College*  
**LONDON**

### **Research Participant Information and Consent Form**

#### ***Women with Bipolar Disorder and pregnancy: a study into the factors influencing their decision-making regarding treatment***

I would like to invite you to take part in a study which aims to investigate the factors influencing women with bipolar disorder when they consider pregnancy. Before you decide whether to take part you need to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

#### ***What is the purpose of the study?***

As part of my PhD, I am investigating what women with bipolar disorder feel they need to consider when making decisions about getting pregnant, and what information might best help them when they are trying to make these difficult decisions.

#### ***Why have I been invited?***

Because you are a woman with bipolar disorder and I would value your views on this subject.

#### ***Do I have to take part?***

No. It is up to you to decide whether or not to take part. I will describe the research study and go through this information sheet, which I will then give to you. I will then ask you to sign a consent form to show you have agreed to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect the standard of care you receive.

NB: If you need general advice about participating in research, you can contact SURE, Service Users in Research Enterprise, based at the Institute of Psychiatry. Contact: 020 7848 0430.

#### ***What will happen to me if I take part?***

If you agree to take part then you will be asked to participate in an interview. The interview will happen at a time that is convenient for you for about 45 minutes to 1 hour 15 minutes. I will ask you to tell me how you feel about having children and whether that has been affected by your illness. If you are thinking of getting pregnant, I will ask you what things you are considering which might affect your decision. I will ask you about any other thoughts you may have about some of these issues. The interview will be taped for analysis after the meeting. Anonymous quotes from the interviews will be used in reports and publications of the findings but no quotes will be used that could identify you to others. We offer a £20 shopping voucher toward your time and any expenses incurred (e.g. travel costs).

*What are the possible disadvantages of taking part?*

The interview may be distressing as it will focus on questions about your illness and the challenges it presents when having children. At the beginning of the interview you will therefore be asked if there is anyone you would like us to contact for support for you if you do become very distressed.

*What if there is a problem?*

If you have any concerns about any aspect of the study, you should ask to speak to the researchers who will do their best to answer your questions. (020 7848 5061). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure Telephone: 020 3228 2444/2499. Email: Complaints@slam.nhs.uk

*Will my taking part in this study be kept confidential?*

All information which is collected about you during the course of the research will be kept strictly confidential. The only exception to this confidentiality will be if you disclose information which suggests a risk of serious danger to any person, in which case the clinical staff involved in your care will be informed. Any information about you will have your name and address removed so that you cannot be recognised from it. Your care-coordinator and GP will be informed that you have taken part in this study unless you state otherwise.

*What will happen to the results of the research study?*

The results of this stage of this study are likely to be published as a report and may also be published as an academic publication. Copies will be available from Seynam Kluvitse, Health Service and Population Research Department, Institute of Psychiatry: Seynam.Kluvitse@kcl.ac.uk You will not be identified in any presentation of the findings.

*Who is organising and funding the research?*

This study is being privately funded and I am a PhD student at the Institute of Psychiatry, which is part of King's College, London, which is sponsoring the study.

*Who has reviewed the study?*

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by the Camden & Islington NHS Research Ethics Committee.  
Contact for further information: Clare Dolman 07530 543403 or clare.dolman@kcl.ac.uk

You will be given one copy of this information sheet to keep with a signed consent form. Thank you for considering taking part in this study.

Study number:

Participant identification number:

## CONSENT FORM

Title of Project: Women with Bipolar Disorder and pregnancy: factors influencing their decision-making regarding treatment.

Name of Researcher: Clare Dolman

**Please initial each statement:**

1. I confirm that I have read and understand the information sheet (version 2 10/10/2011) for the above study. I have had the opportunity to consider the information, and to ask questions. ....
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. ....
3. I agree to take part in the above study. ....
4. I agree to my GP being informed of my participation in the study. ....
5. I agree to my care coordinator being informed of my participation ....
6. I would like to receive feedback on the results of this study. ....

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person taking consent


\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## Appendix 7: Helpful e-forum post about visit to perinatal psychiatrist

**Went to see perinatal pdoc** (Forwarded by A in answer to my thread posted Friday July 11,2014)

[Note: 'pdoc' is e-forum shorthand for psychiatrist and I have replaced all the writers' 'handles' with letters of the alphabet to preserve anonymity]

 by A » Wed Jan 15, 2014 12:04 am

Hi all,

I think I mentioned on here before that I'm getting married later this summer and we want to try for a family. So my regular pdoc got me an appointment with a pdoc from the perinatal psych team so I could ask for advice now. I know I see a few posts on here on what appointments are like and what to do in pregnancy so I thought I'd write a post about the appointment.

The appointment lasted about 45 mins and she started by going through my history. She said she'd read it but she wanted to hear about things from my point of view, as it gave her a better idea than just paper notes. It was a bit painful hearing her talk about some things (and that's coming from me being quite stable right now and having been stable for a good while... so definitely not something I'd have wanted to do if I was feeling crappy). Especially as she went right back to stuff from when I was a young teenager and at uni and asked lots of questions about drug and alcohol misuse (I felt a bit guilty). My partner came with me which was definitely a good thing as he could give more accurate details about my highs than I could... partly because some of it's a blur and partly because I'm pretty embarrassed by my behaviour! And I think it was useful for her to hear more than one perspective.

Afterwards she did a quick overview... and for a second I thought she was questioning the BP diagnosis and that maybe the issues spun from my substance misuse and that I'd be ok now I'm on the straight and narrow. But then she said that despite looking at whether other diagnoses would fit better I had been diagnosed with BP by various doctors over the year and that is how perinatal services would want to treat me. (NB: I asked my partner afterwards whether he thought that she was hinting that I don't have BP and he said all she meant was that she was showing that she'd considered the differential diagnosis when thinking about my case. It took me a long time to accept the BP diagnosis and he has said in the past that I misremember and twist pdocs words to try and prove that I don't have it).

Anyway her advice broke down into the following (which I've written as points)

- \* I'm currently stable on quetiapine (300mg) and lithium (800mg) - I'm also on the oral contraceptive pill
- \* Ideally she wants people off medication when trying to conceive and pregnant
- \* however if someone has experienced psychosis in the past they have significantly increased risks of having an episode during or immediately after pregnancy
- \* a manic/psychotic woman in pregnancy is very difficult to manage medically so it's better to medicate to avoid this if at all possible - since I have experienced psychosis she would therefore recommend I take medication during pregnancy
- \* there is a good body of evidence of the impact for monotherapy with various medications during pregnancy
- \* there is very limited evidence of the impact of polypharmacy during pregnancy and she wouldn't recommend polypharmacy in anything but extreme cases.
- \* so she would recommend medication and it would make sense to choose one from what I currently take (since they're working).
- \* lithium does have risks some of which could be life threatening to the foetus

\* lithium does have risks to the mother as you may need to increase lithium through the pregnancy (due to increased fluid volume) and then you risk toxicity around the post partum period (or risk a relapse if you stop in around post partum period).

\* quetiapine research is starting to demonstrate that it is well tolerated in pregnancy and there's increasing evidence you can breastfeed safely as well (apparently the newer APs show less transfer into breast milk). However she pointed out it is still fairly new so only a few years evidence.

\* quetiapine does have the risk of increased pregnancy weight gain and gestational diabetes

\* In my case she would recommend remaining on the quetiapine (300mg). She would recommend decreasing the lithium by 200mg every two months until I was off it completely. (Which would take me to August, just after the wedding). Waiting one menstrual cycle and then coming off the contraceptive pill. She said if I destabilised off the lithium it should be a choice between increasing quetiapine, or going back on lithium and stopping quetiapine (polypharmacy would only be a last resort).


She says the final decision should be made between me and current pdoc (as he's known me for 3 years) and that I should continue to see him while I'm trying to conceive, but that perinatal psych would want me to be referred back to them once I'm past 12 weeks.

So in summary; really helpful and would recommend for any BP women and definitely worth doing well in advance of trying to conceive. And I would recommend bringing your partner as I would have hated doing it alone. Hope anyone who's interested found this helpful.

XXXX

#### **Responses to this post on e-forum up to Jan 20, 2014**

##### **Re: Went to see perinatal pdoc**


 by B » Wed Jan 15, 2014 6:51 am

A, that was a really detailed post & has helped me so much. I've always been worried about being referred if I was to have another baby, you have eased my fears.

I think that all sounds positive & wish you all the best with your plans 😊

I find the children really help when I'm feeling down, they keep me going. Xxx

##### **Re: Went to see perinatal pdoc**

 by C » Wed Jan 15, 2014 12:24 pm


Brilliant post XXX!!

I remember my perinatal pdoc also questioning my diagnosis as well. And I agree wholeheartedly to take your partner or someone else you trust. They do seem to give you an awful lot of information in a short space of time.

Fingers crossed for later in the year xxxx


Be strong because things will get better..  
It might be stormy now but it can't rain forever!

##### **Re: Went to see perinatal pdoc**

 by D » Wed Jan 15, 2014 4:02 pm

Great post, really helpful - thank you! x

##### **Re: Went to see perinatal pdoc**


 by E » Wed Jan 15, 2014 7:21 pm

v helpful

xx



**Re: Went to see perinatal pdoc**


 by **A** » Fri Jan 17, 2014 10:31 pm

I'm glad it was helpful. Saw my regular pdoc today and discussed the perinatal pdoc recommendations (though he hadn't got a letter from her yet). He did question whether I wanted to start the reduction now or wait as he said he would be concerned about mania as I'd be dropping the lithium completely around the time of the wedding, but I said I thought that I was a lot better in terms of self-management (I'm not drinking or taking drugs, I'm more self-aware about my moods, my partner is more aware and supportive) and would be happy to up Q if necessary. So will be starting the reduction next week (once I've picked up prescription).

XXX x

•

**Re: Went to see perinatal pdoc**

 by **F** » Fri Jan 17, 2014 11:06 pm

Good luck XXX,

That was an excellent post. I remember coming off lithium before I conceived many years ago and it went fine.

**Re: Went to see perinatal pdoc**

by **G** » Sun Jan 19, 2014 11:49 am

Thanks for this. I am currently trying for a baby. I'm on quetiapine. It's always reassuring to know that it's being recommended by other doctors too xx

## Appendix 8: Letter of invitation to Focus Group

Dear delegate

With the approval of my supervisors, Professor Louise Howard of the Institute of Psychiatry, King's College London, and Professor Ian Jones, of Cardiff University, I am holding a focus group of perinatal mental health professionals at the International Marcé Society meeting at Swansea, Sept 10-13, to discuss the factors influencing women with bipolar disorder when making decisions around pregnancy and childbirth.

The focus group will be chaired by XXX and facilitated and recorded by me. It will take place in a lunch hour, venue to be arranged. I will circulate an outline of areas of discussion to be covered nearer to the time.

This will form an important part of my PhD at the Institute of Psychiatry, where I am studying this subject with a view to creating a decision-making tool to help women, their partners and clinicians in making these very difficult decisions. This is the first time this subject has been researched: I have already completed qualitative interviews with 21 women with BD to elicit their views (the preliminary results of which I will be presenting at the meeting), and it would be tremendously valuable to hear what a range of clinicians with experience of these issues regard as the most important factors, and to stimulate a debate on the best way to improve decision-making in this area.

It is likely to be a useful opportunity for those participating to hear other professionals' views and how they might influence their practice in future. If you are interested in taking part, we would be most grateful to receive your expression of interest in the near future so that we can organize a group covering the widest range of experience.

With grateful thanks to the International Marcé organizing committee,

Yours,

Clare

Clare Dolman  
PhD student, Section of Women's Mental Health,  
Health Service and Population Research Department  
PO 31 Institute of Psychiatry, De Crespigny Park, London SE5 8AF  
Chair, Bipolar UK  
[www.bipolaruk.org.uk](http://www.bipolaruk.org.uk)  
Trustee, APP - Action on Postpartum Psychosis  
<http://www.app-network.org>

## Appendix 9 Specialist health professionals' focus group ground rules

### Focus Group Ground Rules:

- ❖ Everyone should have the opportunity to participate and it's important that we hear everyone's ideas and opinions
- ❖ For the recording, it would be helpful if only one person is talking at any one time
- ❖ It is important to create opportunities for both sides of an issue to be discussed
- ❖ All information that is discussed in the interview must be kept confidential
- ❖ We need to make sure that we stay with the main group discussions and do not engage in separate side conversations
- ❖ (Bearing in mind that people are trying to eat their lunch, if you could remove any wrapping before we start it would be a great help with the recording)

## Appendix 10: Information sheet for general adult psychiatrists

### INFORMATION SHEET FOR PARTICIPANTS



REC Reference Number: LRU-16/17-3755

### YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

#### ***Women with Bipolar Disorder and pregnancy: a study into the factors influencing their decision-making regarding treatment***

I would like to invite you to take part in a study which aims to investigate the factors influencing women with bipolar disorder when they consider pregnancy. Before you decide whether to take part you need to understand why the research is being done and what it will involve. Please take time to read the following information carefully and please ask me if there is anything that is not clear or if you would like more information. Thank you for reading this.

#### **What is the purpose of the study?**

As part of my PhD, I am investigating how women with bipolar disorder make decisions about getting pregnant, and what information they need/have access to.

#### **Why have I been invited to take part?**

Because you are a psychiatrist who treats women in this situation and I would value your views on this subject.

#### **Do I have to take part?**

No. If you decide to take part you are still free to withdraw at any time and without giving a reason.

#### **What will happen to me if I take part?**

If you agree to take part then you will be asked to participate in an interview at a time that is convenient for you lasting about 20 – 45 minutes. I will ask you about your experience of discussions with women with bipolar disorder about pregnancy, your opinion on barriers and facilitators to open discussion, and other sources of support you refer women to or would like to see developed. I will also ask you about the perinatal mental health training you received. The interview will be taped for analysis after the meeting. Anonymous quotes from the interviews will be used in reports and publications of the findings but no quotes will be used that could identify you to others. On request, I will send you the report to check that you are happy with the way that any quotes you recognize are reported.

**Incentives (where relevant)**

If you wish, your help with this project will be acknowledged in any subsequent publication.

**How is the project being funded?**

This is part of a self-funded PhD, with additional help from NIHR CLAHRC South London

**What will happen to the results of the study?**

The results of this stage of this study are likely to be published as a report and may also be published as an academic publication.

**Who should I contact for further information?**

If you have any questions or require more information about this study, please contact me using the following contact details: Clare Dolman [clare.dolman@kcl.ac.uk](mailto:clare.dolman@kcl.ac.uk), tel: 07771 835913

**What if I have further questions, or if something goes wrong?**

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact King's College London using the details below for further advice and information:

Prof. Louise Howard, Section of Women's Mental Health, King's College London

Tel: 02078488498 (Section administrator), [louise.howard@kcl.ac.uk](mailto:louise.howard@kcl.ac.uk)

**Thank you for reading this information sheet and for considering taking part in this research.**

## Appendix 11: General psychiatrists' consent form



Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

**Title of Study:** *Women with Bipolar Disorder and pregnancy: a study into the factors influencing their decision-making regarding treatment*

King's College Research Ethics Committee, Ref: LRU-16-17-3755

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by ticking/initialling each box I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes mean that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element I may be deemed ineligible for the study.

☐

1. \*I confirm that I have read and understood the information sheet dated [INSERT DATE AND VERSION NUMBER] for the above study. I have had the opportunity to consider the information and asked questions which have been answered satisfactorily.

\*I understand that I will be able to withdraw my data up to 4 weeks after my interview  
\*I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be handled in accordance with the terms of the UK Data Protection Act 1998.

☐

2. \*I understand that my information may be subject to review by responsible individuals from the College for monitoring and audit purposes.

I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications. I consent to my interview being audio recorded.

☐

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## Appendix 12: Patient Decision Aid quality checklist from the IPDAS Collaboration



### International Patient Decision Aid Standards (IPDAS) Collaboration

#### IPDAS 2005: Criteria for Judging the Quality of Patient Decision Aids

**Steering Committee:** A O'Connor (CA) & G Elwyn (UK) (co-leaders) with A Barratt (AU), M Barry (US), A Coulter (UK), M Holmes-Rovner (US), N Moumjid (FR), H Llewellyn-Thomas (US), M O'Kane (US), R Thomson (UK), D Stacey (CA), T Whelan (CA). **Methods Group:** G Elwyn (leader, UK) with S Bernstein (US), P Shekelle (US), R Thomson (UK), R Volk (US). **Stakeholder Leader:** A Coulter (UK). **Quality Criteria Panels:** A O'Connor (CA) & H Llewellyn-Thomas (US) (editors) with J Austoker (UK), A Barratt (AU), M Barry (US), H Bekker (UK), J Belkora (US), C Braddock (US), P Butow (AU), E Chan (US), A Charvet (Switz), A Clarke (UK), J Davison (CA), J Dolan (US), A Edwards (UK), V Entwistle (UK), A Fagerlin (US), D Feldman-Stewart (CA), J Fowler (US), D Frosch (US), P Hewitson (UK), M Holmes-Rovner (US), T Hope (UK), MJ Jacobsen (CA), A Kennedy (Switz), S Knight (US), M Kupperman (US), B Ling (US), T Marteau (UK), K McCaffery (AU), N Moumjid (FR), A Mulley (US), M O'Connor (US), E Ozanne (US), M Pignone (US), A Raffle (UK), C Ruland (NO), L Schwartz (US), K Sepucha (US), S Sheridan (US), S Stableford (US), D Stacey (CA), D Stilwell (US), V Tait (CA), D Timmermans (NL), L Trevena (AU), T Whelan (CA), C Wills (US), S Woloshin (US), S Zieband (UK).

#### What are patient decision aids and why are they needed?

Patient decision aids are tools to help people participate in their health decisions in ways they prefer. They are used when there is more than one medically reasonable option to diagnose or treat a health problem. Each of the options has good and bad features that people value differently. Even when two people are in the same situation, what is important for one person may be different for another person. Therefore, there is no clear answer that applies to everyone. The best choice involves matching which features matter most to a person with the option that has these features. To make a good decision, you need an expert on the facts (e.g. a health practitioner) and an expert on which features matter most (e.g. the patient) and a way to share their views with each other in ways they prefer.

Patient decision aids aim to do three things to prepare a person for decision making. They provide facts about a person's condition, the options and their features. They help people to clarify their values (the features that matter most to them). They help people to share their values with their health care practitioner and others, so a course of action can be planned that matches their values. Patient decision aids do not advise people to choose one option over another. They do not replace counseling from a health care practitioner. Instead, they prepare people to discuss the options with their health care practitioner.

An international group of researchers, known as the 'Cochrane Review Team of Patient Decision Aids' is compiling decision aids and summarizing the results of research trials. The latest review of 34 studies shows that patients and practitioners who use patient decision aids make better decisions. Patients participate more, know more, and have more realistic expectations of what might happen. They are more likely to receive an option with features they most value (O'Connor et al., *Cochrane Library*, 2003).

The **International Patient Decision Aid Standards (IPDAS)** Collaboration is a group of researchers, practitioners and stakeholders from around the world. The goal is to establish an internationally approved set of criteria to determine the quality of patient decision aids. These criteria will be helpful to a wide variety of individuals and organizations that use and/or develop patient decision aids.

#### Why are standards needed?

There are over 500 patient decision aids available or being developed by many different individuals and groups around the world. However, people have difficulty knowing whether or not a decision aid is a source of reliable health information that can help in decision making.

#### How were the standards obtained?

There was a 2-stage evidence-informed Delphi consensus process

- Participants included 122 people from 14 countries and 4 stakeholder groups [researchers/developers; health professionals/ patient/consumers; policy makers/health plan administrators]
- A voting document was developed from a series of background papers on 12 quality domains. [The experts who wrote these papers are listed above]. Before voting on the importance of each criterion in judging the quality of a patient decision aid, voters reviewed: definition of decision aids; definition of criterion; theoretical link between criterion and decision quality; and empirical evidence supporting or not supporting its use in decision aids. Evidence was derived from fundamental studies and a Cochrane Collaboration systematic review of randomized trials of patient decision aids.

The standards are summarized in a users' checklist on the next page.

**For more information and to obtain copies of the IPDAS documents** visit our website at

[www.ipdas.ohri.ca](http://www.ipdas.ohri.ca)

**Table 3. IPDAS Patient Decision Aid Checklist for Users**

**I. Content: Does the patient decision aid ...**

**Provide information about options in sufficient detail for decision making?**

- ☐ describe the health condition 2.1
- ☐ list the options 2.2
- ☐ list the option of doing nothing 2.3
- ☐ describe the natural course without options 2.4
- ☐ describe procedures 2.5
- ☐ describe positive features [benefits] 2.6
- ☐ describe negative features of options [harms / side effects / disadvantages] 2.7
- ☐ include chances of positive / negative outcomes 2.8

**Additional items for tests**

- ☐ describe what test is designed to measure 2.9
- ☐ include chances of true positive, true negative, false positive, false negative test results 2.10
- ☐ describe possible next steps based on test result 2.11
- ☐ include chances the disease is found with / without screening 2.12
- ☐ describe detection / treatment that would never have caused problems if one was not screened 2.13

**Present probabilities of outcomes in an unbiased and understandable way?**

- ☐ use event rates specifying the population and time period 3.1
- ☐ compare outcome probabilities using the same denominator, time period, scale 3.2, 3.3, 3.6
- ☐ describe uncertainty around probabilities 3.4
- ☐ use visual diagrams 3.5
- ☐ use multiple methods to view probabilities [words, numbers, diagrams] 3.7

- ☐ allows the patient to select a way of viewing probabilities [words, numbers, diagrams] 3.8
- ☐ allow patient to view probabilities based on their own situation [e.g. age] 3.9
- ☐ place probabilities in context of other events 3.10
- ☐ use both positive and negative frames [e.g. showing both survival and death rates] 3.13

**Include methods for clarifying and expressing patients' values?**

- ☐ describe the procedures and outcomes to help patients imagine what it is like to experience their physical, emotional, social effects 4.1

- ☐ ask patients to consider which positive and negative features matter most 4.2
- ☐ suggest ways for patients to share what matters most with others 4.3

**Include structured guidance in deliberation and communication?**

- ☐ provide steps to make a decision 6.1
- ☐ suggest ways to talk about the decision with a health professional 6.2

- ☐ include tools [worksheet, question list] to discuss options with others 6.3

**II. Development Process: Does the patient decision aid ...**

**Present information in a balanced manner?**

- ☐ able to compare positive / negative features of options 9.1

- ☐ shows negative / positive features with equal detail [fonts, order, display of statistics] 9.2

**Have a systematic development process?**

- ☐ includes developers' credentials / qualifications 1.1
- ☐ finds out what users [patients, practitioners] need to discuss options 1.2, 1.3
- ☐ has peer review by patient / professional experts not involved in development and field testing 1.8a, 1.8b
- ☐ is field tested with users [patients facing the decision; practitioners presenting options] 1.4, 1.5

The field tests with users [patients, practitioners] show the patient decision aid is:

- ☐ acceptable 1.6, 1.7
- ☐ balanced for undecided patients 9.3
- ☐ understood by those with limited reading skills 10.6

**Use up to date scientific evidence that is cited in a reference section or technical document?**

- ☐ provides references to evidence used 11.1
- ☐ report steps to find, appraise, summarise evidence 11.2
- ☐ report date of last update 11.3
- ☐ report how often patient decision aid is updated 11.4

- ☐ describe quality of scientific evidence [including lack of evidence] 11.5a, 11.5b
- ☐ uses evidence from studies of patients similar to those of target audience 11.6

**Disclose conflicts of interest?**

- ☐ report source of funding to develop and distribute the patient decision aid 7.1, 7.2

- ☐ report whether authors or their affiliations stand to gain or lose by choices patients make after using the patient decision aid 7.3, 7.4

**Use plain language?**

- ☐ is written at a level that can be understood by the majority of patients in the target group 10.3
- ☐ is written at a grade 8 equivalent level or less according to readability score [SMOG or FRY] 10.4

- ☐ provides ways to help patients understand information other than reading [audio, video, in-person discussion] 10.5



**Table 3. IPDAS Patient Decision Aid Checklist for Users**

Meet additional criteria if the patient decision aid is Internet based

- |  |   |
|--|---|
| <input type="checkbox"/> provide a step-by-step way to move through the web pages 8.1                                      | <input type="checkbox"/> provides security for personal health information entered into the decision aid 8.4          |
| <input type="checkbox"/> allow patients to search for key words 8.2  | <input type="checkbox"/> make it easy for patients to return to the decision aid after linking to other web pages 8.5 |
| <input type="checkbox"/> provide feedback on personal health information that is entered into the patient decision aid 8.3 | <input type="checkbox"/> permit printing as a single document 8.6   |

Meet additional criteria if stories are used in the patient decision aid

- |   |  |
|---|--|
| <input type="checkbox"/> use stories that represent a range of positive and negative experiences 5.2                    | <input type="checkbox"/> state in an accessible document that the patient gave informed consent to use their stories 5.5 |
| <input type="checkbox"/> reports if there was a financial or other reason why patients decided to share their story 7.5 |  |

**III. Effectiveness: Does the patient decision aid ensure decision making is informed and values based?**

Decision processes leading to decision quality. The patient decision aid helps patients to ...

- |  |   |
|--|---|
| <input type="checkbox"/> recognise a decision needs to be made 12.1  | <input type="checkbox"/> be clear about option features that matter most 12.5 |
| <input type="checkbox"/> know options and their features 12.2, 12.3  | <input type="checkbox"/> discuss values with their practitioner 12.6          |
| <input type="checkbox"/> understand that values affect decision 12.4 | <input type="checkbox"/> become involved in preferred ways 12.7               |

Decision quality. The patient decision aid ...

- |  |
|--|
| <input type="checkbox"/> improves the match between the chosen option and the features that matter most to the informed patient 12.8 |
|--|

---

Note: numbers behind items correspond to endorsed criteria in Table 2.

### Appendix 13: Conference presentations disseminating PhD results 2011-2018

Type	Title	Start Date	End Date
Conference Presentation	Madrid 4th World Congress on Women's Mental Health: 'BD and Pregnancy'	16/Mar/2011	19/Mar/2011
Conference Presentation	ENMESH European Healthcare, Ulm, Germany: 'BD + Pregnancy'	23/Jun/2011	25/Jun/2011
Other Talks / Presentations	'More than Baby Blues' Cheltenham Science Festival	15/Jun/2012	15/Jun/2012
Posters	Pregnancy and motherhood for women with SMI review	03/Oct/2012	05/Oct/2012
Posters	NIHR MHRN National Scientific Meeting	20/Mar/2013	22/Mar/2013
Conference Presentation	UK Ireland Marcé Society meeting: 'BD + pregnancy decision-making'	19/Sep/2013	19/Sep/2013
Conference Presentation	ENMESH Conference Verona: Systematic Review results	03/Oct/2013	05/Oct/2013
Other Talks / Presentations	Presented at London Perinatal MH Network Launch on BD and pregnancy	15/Oct/2013	15/Oct/2013
Other Talks / Presentations	Presentation at WMH Special Interest Group meeting: 'SMI and pregnancy'	27/Nov/2013	27/Nov/2013
Other Development Activity	Presented at Centre for Affective Disorders IOPPN launch: Bipolar + relationship with Health professionals	31/Jan/2014	31/Jan/2014
Other Development Activity	SHIMME conference on shared decision-making, Cambridge	19/Mar/2014	19/Mar/2014
IOPPN, King's College Teaching (GCAP)	MSc Res Methods Women's Mental Health module: S. User Research, PhD = example	07/Apr/2014	07/Apr/2014
Conference Presentation	EPA conference Ulm, Germany	21/May/2014	23/May/2014
Other Talks / Presentations	Bart's Academic Afternoon for medics: BD + Pregnancy	05/Mar/2014	05/Jun/2014
Other Talks / Presentations	BD and pregnancy - a service user perspective, King's Summer School	18/Sep/2014	18/Sep/2014
Seminars	MHQRN meeting 'shared decision making for psychiatrists'	02/Oct/2014	02/Oct/2014
Conference Presentation	Women and Mental Health, 'Feminism in London' Conference	25/Oct/2014	25/Oct/2014

Conference Presentation	BD: a Service User Perspective, RC Psych's BD Interest Group annual meeting	27/Oct/2014	27/Oct/2014
Conference Presentation	'What women want from psychiatrists', RC Psych Perinatal Faculty Annual Meeting	20/Nov/2014	20/Nov/2014
Conference Presentation	World Congress on Women's Mental Health Tokyo: BD/pregnancy PhD results	22/Mar/2015	25/Mar/2015
Presentation - midwives	Lecture to St Thomas' WMH Research Grp: PhD findings	14/May/2015	14/May/2015
Conference Presentation	'Living with a psychiatric disorder over Time' Interdisciplinary Conference, Law/Philosophy, Kings	01/Sep/2015	01/Sep/2015
Conference Presentation	ENMESH international MH conference Malaga: PhD results	01/Oct/2015	03/Oct/2015
Conference Presentation	Wales Perinatal Conference, Cardiff with Health Minister: importance of preconception advice for women with BD	10/Mar/2016	10/Mar/2016
Conference Presentation	'BD and Pregnancy' West London Perinatal MH Conference	18/Mar/2016	18/Mar/2016
Public Presentations	Hay Festival talk on Bipolar Research	01/Jun/2016	02/Jun/2016
Other Development Activity	Facilitating workshop on BD and pregnancy, Bipolar UK, London	18/Jun/2016	18/Jun/2016
Conference Presentation	BD pregnancy decision-making, ISBD, ISAD Amsterdam	13/Jul/2016	14/Jul/2016
Conference Presentation	'BD and pregnancy' International Marcé Conference, Melbourne, AUS	26/Sep/2016	27/Sep/2016
Health professionals PMH training	'What women want from psychiatrists' included PhD research, RCPCH training	20/Dec/2016	20/Dec/2016
Health professionals PMH training	Bipolar + Pregnancy: 'what women want', Royal College Psychiatrists' training	30/May/2017	30/May/2017
Other Talks / Presentations	'Bipolar + Pregnancy' - NHS Providers Conference	08/Jun/2017	08/Jun/2017

Conference Presentation	'BD + Pregnancy: Factors influencing D. making' International Congress of Women's Mental Health, Dublin	06/Mar/2017	08/Jun/2017
Health professionals PMH training	Midwives, GPs, HVs, psychiatrists At Birmingham for RCPSYCH Perinatal Faculty	21/Nov/2017	21/Nov/2017
Conference presentation	'BD + pregnancy decision-making, patient + professional perspectives' International Marcé Conference Bangalore	27/Oct/2018	29/Oct/2018
1 Day Service User perspective on RCPsych PMH training	Organised + presented one day module to psychiatrists on bursary perinatal training, RCPSYCH	05/Dec/2018	05/Dec/2018